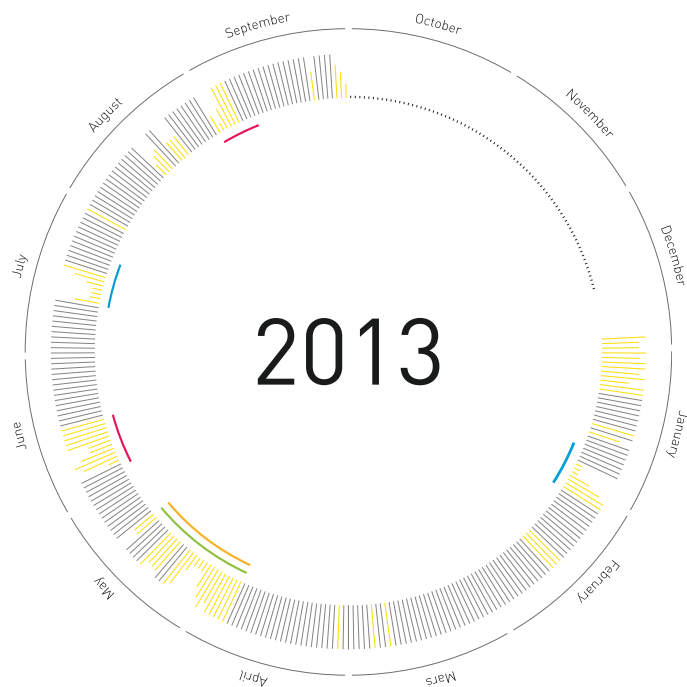


COLLABORATION IN CARE

DESIGN OF A MOBILE HEALTH PLATFORM TO
SUPPORT CARE MANAGEMENT OF CYSTIC FIBROSIS

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ABSTRACT

THE NOTION OF healthcare is today not restricted to the boundaries of care institutions. IT-based health services, or the so called eHealth sector, are developing rapidly, enabling for patients to be actively involved in their care in new ways. Information technology, connecting the private and the professional spheres, brings new opportunities for co-production of care. These opportunities can be especially valuable for patients with chronic disease, who have an ongoing relationship with their care providers. The hypothesis in this thesis is that the practice of design can contribute to these emerging e-health service systems, in creation of services aiming to be desirable and meaningful, both in the professional and in the private spheres.

This thesis explores the possibilities for a mobile application to support patients and families, living cystic fibrosis, in their daily life with illness and in collaboration with their professional care providers.

Through a literature review I aim to give an overview of the context for design, and an understanding for practices, theories and trends relating to chronic disease management in relation to development of information technology and digital health services. Insights from literature have informed and inspired the practical work, focusing on the context of Swedish CF care.

In my design process I have primarily taken the approach of empathic design which focuses on understanding and empathizing with peoples experiences to seek insights, practices and problems, in order to find opportunities for design. Tools and methods from the field of service design have been applied to understand the holistic view of how a mobile health application can be integrated into the context of healthcare, to seek opportunities for how such application can support in points of interaction between patient and healthcare professionals.

My findings support previous research in design of technology for healthcare, to design for enskilment and learning related to daily life. A concept for the application has been designed with the findings from my research as a base, which emphasize documentation and sharing of observations of daily living as a base for collaboration. The concept is prototyped and tested with future users, utilizing approaches from experience design. The conclusion in this thesis does not suggest fully designed solutions, but to design platforms for collaboration, enabling for patients and families to work together with healthcare professionals to remove barriers for healing.

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1. INTRODUCTION

1.1. A PARADIGM SHIFT FOR HEALTHCARE

IT IS 2013. The past few years there has been an almost explosive development of mobile health applications for personal use. Mobile technology enables individuals to gain personal information and increased awareness of their health in various ways. These applications and services range from fitness promotion to more specific disease management support. The new possibilities of using information technology within healthcare is often referred to as Health 2.0 or eHealth and is seen to have a huge potential to improve and renew healthcare to become more personalized and participatory (Swan, 2009, Steinhubl et al., 2013).

A majority of the emerging health related applications are stand-alone services, not connected with healthcare providers' information systems. To reach the full potential of what is called Health 2.0 it is seen vital to enable integration of external health applications to official healthcare systems (Statsrådsberedningen, 2013). Only recently the infrastructure for data sharing between external mobile applications and the national healthcare's IT system has been implemented in Sweden. This opens up for a paradigm shift in society and within the healthcare system, where patient and care provider can exchange detailed individual health information. New channels of interaction between patient and clinician could enable patients to be more involved and engaged in their own care, and increase health literacy. Health literacy is the ability to acquire and understand information about the personal health, which is fundamental to patient engagement and empowerment (Coulter and Ellins, 2007).

To enable and support engagement in care is especially important when it comes to patients with chronic diseases. These patients have an ongoing relationship with their care providers, although most of the care is self-management at home. Evidence show that patients' engagement and involvement in their own care can result in higher self-esteem and self-efficacy and have a positive effect on self-management and outcome of care (McWilliam, 2009). One can also see the possibility that if clinicians were provided with more detailed and nuanced information from their patients, this could provide new sources of information and new forms of collaboration that can contribute to advances in clinical practice and research.

1.2. THESIS FRAMEWORK

1.2.1. DESIGN FOR MOBILE HEALTH SERVICES

IN SWEDEN, THE eHealth sector is developing rapidly, even enabling for mobile application based services to be integrated into the national healthcare system (Vinnova, 2013). I believe the practice of design contribute to these emerging e-health service systems both in the professional and in the private spheres. Design can help establish services that are meaningful, desirable and valuable to both patients and healthcare professionals.

This thesis studies the service possibilities in healthcare enabled by information technology and connects research to a design project. The project aims to identify design opportunities for a mobile application meant to support patients and families living with a particular chronic disease in their daily life with illness and in interaction with healthcare providers. From identified opportunities, a concept for a next version of the application is proposed.

A literature review is made to provide an understanding for the context of such application, and what is seen to be the opportunities, benefits and challenges for future healthcare services as information technology enables service innovation.

Concepts and theories relating more specifically to the context of chronic disease management are studied to inform design. The literature review will draw insights from international studies to inform the project which is otherwise solely focusing on the context of the Swedish healthcare system, and more specifically, care for patients with cystic fibrosis.

1.2.2. PROJECT CONTEXT

About cystic fibrosis

CYSTIC FIBROSIS is a very rare disease, and not very known to the public. Therefore, I give a short introduction to cystic fibrosis and the patient's daily treatment, to provide an understanding of the context of my work.

Cystic fibrosis (or CF) is an autosomal recessive genetic disorder that affects most critically the lungs. When diagnosed with CF, the mucus-producing glands in the body are not functioning properly, the mucus is too thick, which causes many problems, e.g. breathing problems, lung infections and difficulty in assimilating the food. CF requires burdensome daily treatment in order to slow deterioration. (Socialstyrelsen, 2013)

Patients and families are working hard to limit the short-term and long-term negative impacts of CF in everyday life. If the disease process is reasonably under control, most of the actual treatment is self-care at home. Treatment is often burdensome since it requires up to two hours per day of medication, respiratory- and physical exercise. This treatment should be followed everyday, 365 days a year.

Symptoms and state of health varies individually, the severity is determined largely by how much the lungs are affected. Still, deterioration is inevitable as lung function and exercise tolerance declines. 50 years ago, it was rare that patients lived through childhood, but as medical treatment progress the prognosis for life expectancy is also improving. For children born with CF in Sweden today, there is a now a positive prognosis for growing old. (Vårdguiden, 2013, Socialstyrelsen, 2013).

Since CF is a genetic disease, it is not equally spread all over the world, it is most common in Europe and amongst people with European origin in the United States. In the US, approximately 30,000 individuals are diagnosed with CF. Within the European Union, 1 in 2000–3000 newborns is found to be affected by CF according to WHO (WHO, 2013). In Sweden, there are today approximately 600 patients diagnosed with CF. (Socialstyrelsen, 2013)

About Chimes

THE PROJECT in this thesis has its starting point in individual experiences of the difficulties in living with cystic fibrosis and in the need to ease collaboration with professional care providers, to co-produce

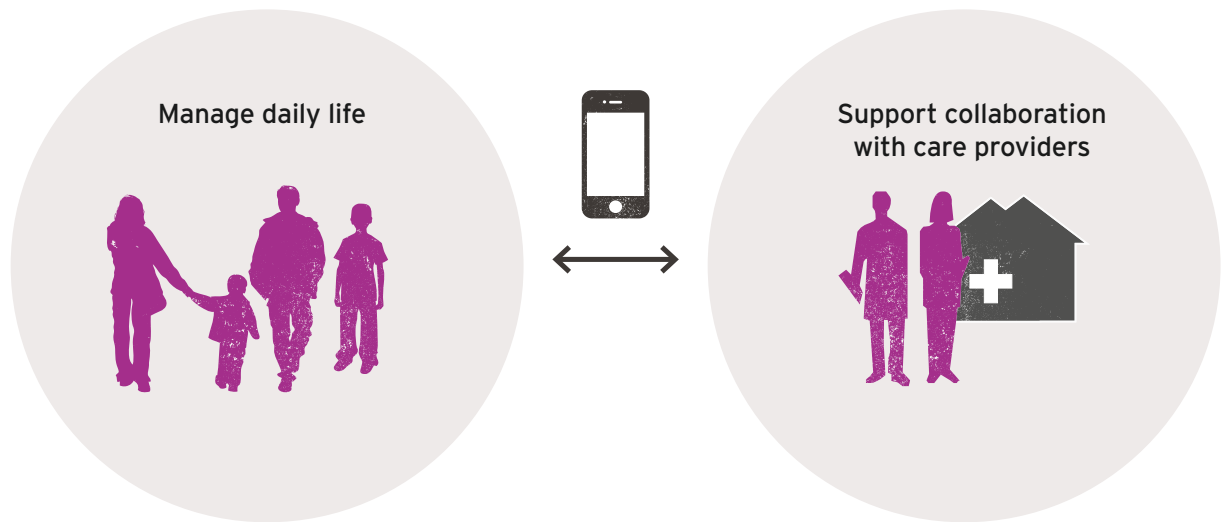
care. The project was initiated by the Swedish company -- Chimes -- who works according to the following mission statement:

”Our aim is to reduce the burden of illness for patients and families with long-term illness by radically improving the ability of patients, families and professionals to co-produce improved clinical practice and better care at home.”

Chimes has developed a prototype of a smartphone application named Genia, for children with cystic fibrosis and their families. The founder of Chimes has a daughter with cystic fibrosis, and the need for Genia came from personal experiences about difficulties in communicating experiences from everyday life to clinicians, understanding disease symptoms together and the ongoing challenge to find the right and best individual treatment. Only personal means and interests had so far driven the work, that started in 2009. In the creation of a next version of the application, there was a strong need, from Chimes part, to understand the motivations and needs of the user group more in depth. This was seen as essential in order to create an application that would be attractive to the target group. In addition, as a piloting project, Genia will be one of the first so-called third party applications to be connected to the Swedish healthcare system via the national eHealth infrastructure. This connection requires an understanding for the healthcare context and what information and interaction that can support both patient and care provider for successful implementation.

1.2.3. DESIGN APPROACH

THE PROJECT In this thesis aims to present a concept for design of a future version of the Genia application. The end-user perspective has been a starting point for Genia, both being a lead user initiative, and also in this thesis. A strong human centered design approach, focusing on empathic design, has been undertaken in order to gain understanding for the challenges and experiences of living with cystic fibrosis, both as a patient and as a caregiver. Human centered design builds on cooperation with and learning from potential future users with the aim to design products or services that match user needs, practices and preferences (Steen, 2011). Human centered design is a broad notion which comprises different approaches which often overlap (ibid). In this study I have primarily taken the approach of empathic design, which focuses on individual everyday life experiences, moods and emotions, and on turning such experiences into inspiration for design



(Mattelmäki et al., 2014). The design research in this thesis aims to seek insights in everyday life practices and problems when living with cystic fibrosis, and what motivations the target users have for using a mobile application as support in daily life, in order to find opportunities for design. This view comprise not only the personal sphere, but also the interaction with care providers.

Since the application aims to link between the personal and professional spheres, the design work requires an understanding of the existing organization for CF-care and the stakeholders involved. To gain this understanding, methods and tools from the field of service design is applied. Service design builds on the human centered approach, but takes more holistic perspectives (Sangiorgi and Meroni, 2011). Service design offers methods to understand and design service systems with focus on the user experience and the interaction between involved stakeholders (Mager, 2008, Sangiorgi and Meroni, 2011). In this thesis methods from the field of service design are applied to map and understand the healthcare context of CF-care, what possible value Genia could bring to the different stakeholders, and seek opportunities for how Genia could improve points of interaction between individuals within this system.

FIGURE 1.1
The idea of Genia bridging
between the personal and the
professional sphere.

1.2.4. OBJECTIVES

The thesis objectives are to:

- 1) Understand the context of design for a digital health application, intended to assist patients and families living with cystic fibrosis.
- 2) Gain insight in how children and their families experience daily life with cystic fibrosis and how they interact with their healthcare providers.

This is done a) through a lens of evaluating the existing concept of the application and b) for seeking design opportunities for a (improved) mobile application to be a support for children and their families in managing daily life with disease and in interaction with healthcare providers.

1.2.5. RESEARCH QUESTIONS

THROUGH A LITERATURE review and a design project this thesis thus aims to find answers to following research questions:

What are the opportunities for a mobile application to support children and their families in managing daily life with cystic fibrosis?

How can a mobile application support interaction between patients and care providers, and co-production of care, when the target group is children with cystic fibrosis and their parents?

2. LITERATURE REVIEW

2.1. CONTEMPORARY ANALYSIS

This section aims to give an overview of current tendencies of change within the area of healthcare and how healthcare services are developing in the era of digitalization.

2.1.1. DIGITALIZATION OF HEALTH

THE CONCEPT OF healthcare is today not restricted to the boundaries of care institutions. Internet has enabled for increased information sharing between individuals, and the concept of open source health platforms has grown tremendously the past ten years (Swan, 2009). These platforms and communities have given people the means to share information and experiences concerning health and illness between each-other. Also platforms that allow for storage and analysis of personal health data are expanding, where one can keep personal logs of symptoms and measurements (Swan, 2009). Simultaneously new advanced technology enables individuals to measure and track the personal health in totally new ways, with the technology available in mobile phones. There has been almost an explosive development of smartphone applications for health promotion and disease management in the past few years.

Platforms for interaction accompanied by advanced technologies enables for increased awareness of the personal health and how to improve it. This development is foremost consumer driven, and a majority of the services and applications are commercial inventions from private companies. From one perspective, these consumer driven

services, embracing a larger concept of health and wellness to also include the preventative stages, and which enables individuals to be more informed about their health, can be seen as a shift towards a more patient driven healthcare model (Swan, 2009). However, even though technology enables individuals to be more engaged in and aware of their own health, there is still a gap between the private and the professional sphere when it comes to how personal health data is used in clinical practice.

Great potential is seen in linking services used for personal health management to care providers' information systems, allowing for exchange of data to benefit both the patient and the care provider in the delivery of professional healthcare (Tang et al., 2006, Christensen et al., 2009).

2.1.2. E-HEALTH

THE POSSIBILITIES FOR new service models within public healthcare, connecting patient and provider through information technology, are often called eHealth. The e in eHealth is stated to imply a variety of meanings for what these services should characterize, apart from electronic. The e suggests as well as efficiency and enhanced quality, also empowerment, encouragement and education (Eysenbach, 2001). Hence, apart from only being a new way of service delivery, eHealth is seen to stand for more personalized and participatory healthcare services. The opportunities for eHealth to increase access and quality of care are globally recognized, and within the European Commission, strategies are set up for development of eHealth services both nationally and internationally (Europeiska kommissionen, 2013).

2.1.3. PERSONAL HEALTH RECORDS

ONE CORNER STONE in the Swedish public eHealth strategy, is the development of personal health records (Statsrådsberedningen, 2013). Personal health records are platforms where individuals can keep information and data of their personal health online. Unlike the professionally managed patient records, a personal health record is managed by the individual, and allows for capturing of data and personal information related to the personal health. The term PHR have existed since the 1960's in academia and then referred to personal records in the most basic sense, such as simple notes made by

patients, containing information needed in order to be informed about ones health (Jeongeun Kim et al., 2011). Technology development has allowed the concept of PHR to grow in both functionality and applications and today global companies offer online services for personal health records. One example of such service is Microsoft HealthVault (Microsoft HealthVault, 2013). These online platforms allow for storage of personal health information, with ability to connect the personal account to devices and mobile applications, for the user to collect data of own interest. Keeping records of the personal health is shown especially beneficial for self-management of chronic disease, as it can increase patients' knowledge and provide a sense of control (Tang et al., 2006).

Tang and colleagues highlight the potential of personal health records to increase patient engagement and involvement in care, but recognize that the potential benefit of PHR systems to bridge between patient and care provider depends on to what degree the personal record is being integrated with the providers' patient record. Tang and colleagues envision an environment where health information can flow seamlessly and securely between professionals, caregivers and patients, and their different systems, based on the patient's decision. Similarly Christensen and colleagues highlight the importance of developing solutions that allow for information to travel with the patient instead of being kept with the care providers to reach an efficient and high quality healthcare system (Christensen et al., 2009). Christensen describe a concept similar to social networking sites like Facebook, where only whom you allow can see your information. These concepts of seamless information sharing between patient and care provider are not easy to implement. Problems on both technical and policy level are recognized to need solutions, in order to generate trusted data exchange between formal health-care organizations and external third party services (Patricia Flatley Brennan, 2010).

Personal health record - the Swedish context

IN 2012, THE Swedish Ministry of Health initiated the process of creating a personal health record for each citizen, based on a government decision. "The Government's assessment is that a personal health record online will be an effective support for individuals in the planning, implementation and monitoring of lifestyle changes as well as the health-related events" (Statsrådsberedningen, 2013).

The personal health record should provide opportunity for citizens to collect and store personal health data through the use of 3rd party services and devices. The Personal Health Record will be connected to an established national online platform for health services, Mina vård-kontakter, to provide exchange of information between care provider and citizen. However, the platform for the national PHR system is not yet established at the time of writing, launch is planned some time during 2014 (Statsrådsberedningen, 2013).

2.1.4. CO-PRODUCTION, A NEW MODEL OF SERVICE DELIVERY

IN PARALLEL, AND perhaps intertwined with the new service possibilities that comes with formation technology, there is an ongoing debate around the public service model and how it needs to transform. In welfare states all over the world public healthcare systems are facing a big challenge in delivering high quality care to the same cost as before. An increasing number of people living with chronic disease, a growing elderly population and a dysfunctional global financial system are factors putting the healthcare systems under pressure (Boyle and Harris, 2009, Finansdepartementet, 2004). The traditional healthcare service model, where professionals perform care delivery and patients are seen as passive recipients of advice, is recognized to not be a sustainable model for the future. New types of service models are seen as crucial for maintaining a functioning public healthcare system (Finansdepartementet, 2004). Public service models building on co-production have been promoted by policymakers and researchers to have the potential of being more economically sustainable, produce better outcomes and improve wellbeing, in comparison to traditional service models (Cottam and Leadbeater, 2004, Burns et al., 2006, Bovaird, 2007, Boyle and Harris, 2009).

The essential meaning of co-production in public services is that users are seen as resources and active participants in both design and delivery of service, in a shared partnership with professionals where experiences and knowledge is exchanged (Boyle and Harris, 2009). The notion of co-production is also seen to entail a different value creation model than the traditional healthcare model. Instead of only seeing value as the economic notion of productivity and efficiency, the value creation for the customers or users should be at the core, where offerings are co-designed together with the user, to harness the individual's own competence and resources to co-produce value (Normann, 2006a).

The co-production model demands from the individual to take more own responsibility for his or her health, and instead of being a passive receiver, takes active part in decision-making and delivery of care. Thus, in the context of healthcare, the co-production model is quite naturally not suitable at all times. There are clear situations where the traditional roles of provider and receiver should not change. An individual who has been in an accident, and who needs acute surgery performed by professionals and cannot be part of co-producing his or her care, this is what is called relieving logic (Best and Harries, 2006). In contrast, co-production is seen to be an under utilized model in preventative care, where individuals could benefit from being enabled to co-produce their own health in cooperation with health professionals, in what is called enabling logic (ibid). The variations between relieving and enabling logic are recognized to need adaptation to context (ibid). Normann and colleagues highlight that co-production requires a deeper knowledge of the user, since value is created when the individual's needs, values, competences and resources are combined with the resources and competences of the care system. Hence users should not only be seen as patients but as 'whole' individuals (Arvidsson, 2006).

Several authors acknowledge that there are many challenges and barriers to overcome in order to establish co-production models in public health systems (Nesta, 2012, Boyle and Harris, 2009, Normann, 2006b). If looking critically, one can ask if co-production models are suitable for all types of cultures and societies. How does co-production fit the Scandinavian welfare model, building on terms of citizens' equal right to healthcare? Normann acknowledges that there is a risk of inequality, since users have different resources and knowledge, hence one challenge is to create opportunities for co-production in groups that, in different aspects, are weak regarding resources (Normann, 2006b).

2.1.5. WHAT IS DRIVING CHANGE AND WHERE DOES IT HAPPEN?

INFORMATION TECHNOLOGY IS seen as an important enabler for co-production and innovation in healthcare (Christensen et al., 2009, Normann, 2006a). One can see a high belief in the potential of technology to radically change healthcare, where mobile technology enables individuals to self-diagnose and monitor their health, and become more engaged in their care (Steinhubl et al., 2013). However, even if acknowledging the potential of technology, there are arguments

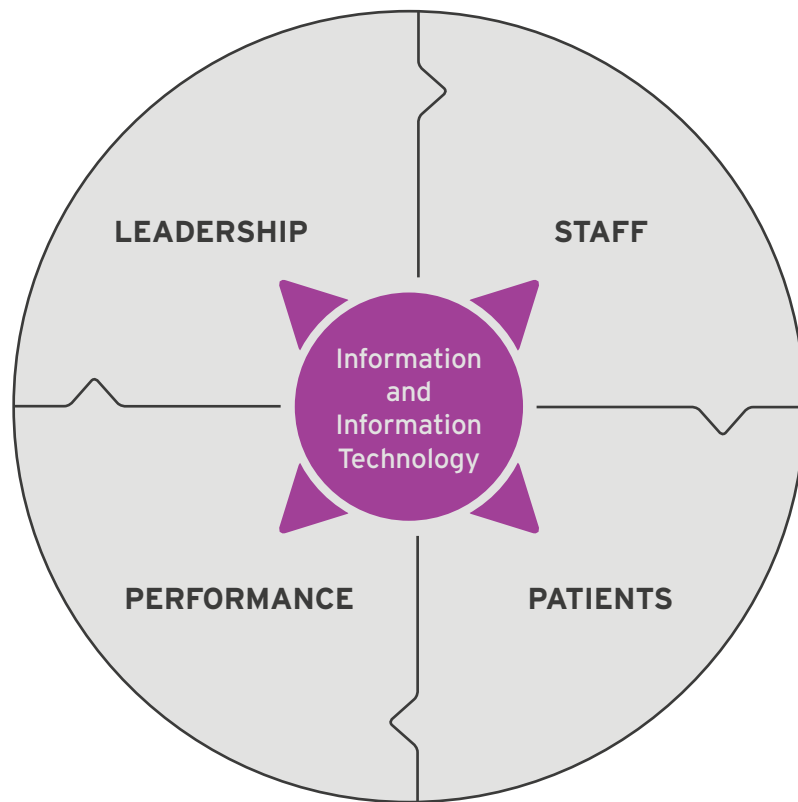


FIGURE 2.1
The Clinical Microsystem
 Adapted from Nelson et al. 2003.
Microsystems in Health Care: Part
2. Creating a Rich Information
Environment. Joint Commission
Journal on Quality and Safety,
 29, 5-15.

against development to be *driven* by technology. In his book *Design for Care*, Peter Jones highlights the importance of focusing on designing human-centered care systems (Jones, 2013). Jones argue not to celebrate innovation for its own sake, but to carefully consider the intent of innovation and whose values are being optimized.

“We might reframe the purposes of “disruptive innovation” in institutional healthcare from economical and technical value to that of co-creating significant service transformations that benefit all the stakeholders” (Jones, 2013, Chapter 8, *Disruptive Transformation, The Healthcare Innovator’s Challenge*)

Also Normann and colleagues stress that technological innovation must be followed by social and institutional innovation, for changes to be realized and successful, and that future service innovation should be driven by the objectives and values of real service users. The approach of empathic design in innovation processes is emphasized, in order to design offerings which create real value for users (Best and Harries, 2006).

Healthcare systems are large and changes are recognized to be difficult to facilitate and implement (Sanandaji, 2012). Medical scholars suggest that clinical microsystems is the appropriate place and agent for change of practice and improvement within the care system (Batalden et al., 2006). Clinical microsystems are the small units that work in front lines of healthcare, which includes different roles such as patients and providers, but also the information and technology used in the system for a shared purpose. The clinical microsystems comprise the people who have the knowledge and practical means to make changes in practice, and holds the patient and the population at the center. Batalden and colleagues also point out to recognize that patients and providers are part of the same system, which contrast the idea of giving care to instead of with the patient.

2.1.6. DESIGN FOR SERVICES

THE APPLICATION OF design in improvement and innovation of public services have been encouraged and acknowledged by several authors (Sangiorgi and Meroni, 2011, Burns et al., 2006). Design can be applied both in the creation of services that puts the users at core, but also as a method to enable collaboration between a variety of stakeholders (Sangiorgi and Meroni, 2011, Burns et al., 2006).

Service design, is a varied field, since design methodology can be applied in different levels of a service system and with different aims. The service design process can either focus on improving interactions and experiences, or be applied in a more strategic level for larger organizational change. However, the core in service design, and common for all levels of application, is the human centered approach, to understand and focus on the people (users, service staff or other stakeholders). Essential for practice within the field of service design is to investigate and understand the experiences, interaction and practices of people, which becomes the source of inspiration in re-design or design of new services. (Sangiorgi and Meroni, 2011)

Since the people involved are experts of their own experiences, a common approach is to invite users and other stakeholders to participate in the design process, in so called co-design or co-creation, both for understanding current practices and for envisioning future possibilities (Sanders and Stappers, 2008). With the change towards co-created services within the healthcare sector, the role of designers is simultaneously changing. Freire and Sangiorgi mean that designers

must give power to the collective of co-creation by designing entities that give room for adoption and adaptation (Freire and Sangiorgi, 2010). It has been described as shift from considering ‘Design before use’ to ‘Design for Design after Design’ (Ehn, 2008).

In the case of this thesis, the design work is not aiming to change the service organization for CF-care, instead it focuses on design of an ICT-application, where one aim is to improve points of interaction between individuals who are part of the same clinical microsystem. By designing means for improved interaction between care provider and patient, the work aims at creating better conditions for co-production of care. Thus, my work requires an understanding both for the holistic picture of the existing service organization for CF-care and the involved stakeholders, as well as knowledge about individuals’ activities and experiences.

2.2. PRACTICES AND THEORIES INFORMING THE PROJECT

This section describes practices and theories related to health management of chronic disease to further inform the project in this thesis.

2.2.1. THE QUANTIFIED SELF

A MAJORITY OF commercial applications for personal health promotion are built around the same strategy, logging of personal data. Even if the purpose varies, e.g. to monitor calorie intake for weight loss, track physical exercise to get fit, or to regularly measure blood pressure to avoid heart problem, the core is self-monitoring. Keeping notes about one’s health is shown to be a tool for improving it (Giffin et al., 2003). Even the process of tracking itself can have positive impact on behavior since it creates an understanding and awareness around one’s own actions that can lead to a positive behavioral change (Klasnja and Pratt, 2012, Kopp, 1988). Almost all of us track ourselves, more or less knowingly. In its simplest form self-tracking can be a pair of skinny jeans in the closet that you try on to see if they still fit, or stepping on to the scale every once in a while. On the extreme, the advanced self-tracker uses wearable sensors and devices to collect, store and analyze huge amounts of personal data about daily routines. There is even a

movement around self-tracking, called Quantified Self, where engaged self-trackers join in their shared interest of using technology for tracking and interpreting data from daily life (Quantified Self, 2013). The members are driven by the belief that by reflecting over gathered personal data one can learn about oneself and also improve.

Members of the quantified self-movement are not only focusing on health related aspects, but are devoted to the tracking as phenomena. However, in general self-tracking is more common amongst people living with one or more chronic conditions than amongst people with no chronic condition (Fox and Duggan, 2013). When it comes tracking of personal health, research from the United States show that people who take formal notes of their health are more likely share their progress with a clinician. Younger people more often use apps or other devices for tracking compared to older adults (Fox and Duggan, 2013).

Self-tracking is often part of self-care for people with chronic conditions, and promoted by clinicians. Diabetes patients have been tracking blood glucose and insulin intake for decades, on clinicians' advice (S. Walford, 1978). Mobile technology have made self-monitoring less burdensome, and as development progresses, much of self-monitoring can be done through passive data collection, where no active input is needed from the user.

Negative effects of self-tracking

ONE CAN ALSO pose a question if the concept of self-tracking is only positive for one's health and wellbeing? Self-monitoring doesn't only increase personal awareness; it can also amplify a sense of success or failure about oneself (Peel et al., 2003). In a study about self-monitoring of blood-glucose for diabetes patients, some patients reported that they felt obsessed and paranoid about their readings. Increased self-responsibility was often accompanied by increased self-blame and negative emotional reactions to negative results (Peel et al., 2003). Another study, also on diabetes patients, show similar results, where self-monitoring was by some patients perceived as an enemy that lowered their self-esteem and caused anxiety (Hortensius1 et al., 2012). Even if self-monitoring can result in a positive outcome on health, the need has to be balanced with the burden of monitoring, when used in self-management of care. Mutually agreed goals and tailored monitoring, as well as ensuring that patients understand the purpose of monitoring and how the readings should be interpreted is seen to be important for most positive effect (Hortensius1 et al., 2012, Peel et al., 2003).

2.2.2. OBSERVATIONS IN DAILY LIVING

AS DESCRIBED PREVIOUSLY, the concept of personal health records, where health information is kept with and by the patient, is seen as essential for both improving patient engagement in care, but also for quality improvement in healthcare. Project Health Design, a national program in the United States, funded by the Robert Wood Johnson Foundation, has done extensive research and design on the concept on personal health records (Patricia Flatley Brennan, 2010). The initiative, being a eight-year long project, aimed to stimulate innovation of personal health records that can guide daily health decisions and empower individuals to manage their own health better. In Project Health Design, interdisciplinary teams applied user centered design methods to create new solutions for PHRs aiming to bridge between the patient experience and provider expertise. The work conducted by the teams provides several examples of how design competence, such as a user-centered focus, making things visual and prototyping can be used in innovation around new health services.

One of the major insights that came from Project Health Design was the importance of day-to-day data, (Observations of Daily Living, ODLs), to be included in personal health records. ODLs are personal signs that people attend to in their daily life, that inform them about their health, and to take action. In comparison to monitoring of clinical data, often guided by clinicians, ODLs are defined by patients and their families, from what is meaningful for them. Observations of daily living are foremost seen beneficial for the patient, as a way to gain awareness of the personal health and to make informed decisions. However evidence also show potential benefits of incorporating ODLs into clinical practice. It is recognized that ODLs can provide clinicians with a more detailed picture of an individual's personal health experience, hence give a richer picture and understanding for the patient's context. (Patricia Flatley Brennan, 2010, Backonja et al., 2012)

2.2.3. POTENTIAL AND CHALLENGES FOR E-HEALTH TO BRIDGE BETWEEN HEALTHCARE INSTITUTIONS AND HOME

FOR PATIENT WITH chronic conditions, management of disease and treatment is part of everyday life. Supporting the integration between the healthcare context and home hence becomes an important matter

to facilitate disease management. Not only in the sense of enabling exchange of health data, but to ease disease management to be integrated in everyday life practices of the individual. Both opportunities and challenges in bridging between the domains of healthcare and home are recognized in projects for design of healthcare technology.

Technology as a boundary object

A PILOT STUDY in design of an e-diary aiming to support self-management of care for pregnant women with diabetes showed how technology can function as a boundary object between the domains of the patient and the healthcare provider (Aarhus et al., 2009). The concept of a boundary object is described as an object carrying information which can have different meaning and use in different social worlds, but which is still robust enough to keep a common identity across communities (Star and Griesemer, 1989).

The women in the study were instructed to monitor and note down their blood sugar level in an electronic diary during their pregnancy. This could be done with the use of a smartphone or a computer. Every fortnight the women had a consultation with their care providers about their health. The women were guided on how to interpret their values by the clinicians, and could themselves act upon them and adjust their insulin intake accordingly. Simultaneously the clinician could evaluate the prescribed treatment, which increased the quality of the treatment. The women found the use of the phone easier to use in everyday life than traditional diabetes diaries, which usually are in the shape of paper and pen. The eDiary, bridged the spheres of home and hospital, although the use and meaning of the eDiary varied between the settings. The challenge recognized for technology to function as such boundary object between home and hospital was to create a design plastic enough to match both domains and users, although as robust to be recognizable and seen beneficial by both groups. (Aarhus et al., 2009)

Design for everyday life practices

SIMILAR CHALLENGES WERE seen in one of the projects in Project Health Design (Chira et al., 2010). In a project called Living Profiles, the aim was to design a teen-oriented personal health record. Thorough user inspired design with teenagers revealed the importance of a personal health record to reflect the teens' individuality and perceived quality of life, which might not be reflected to their

care providers during a typical clinical visit (ibid). To get one's identity restricted to the role of 'a patient' is acknowledged as an experience that can result in loss of self-esteem and feeling of loneliness (Ballegaard et al., 2008). In order to increase adoption of usage of the PHR, it was also seen crucial to align and integrate the PHR with typical behaviors of the teenagers. The final design concept was a media platform that integrated multiple tools and devices to assist the teens in health and wellness management, which also reflected the teenagers' personal identity. It was acknowledged that the impact of the PHR would be reduced if not integrated into clinical practice. However, the providers' use and acceptance of such PHR into clinical workflows was not accounted for within the frames of the project. (Chira et al., 2010)

2.2.4. GUIDELINES FOR DESIGN OF HEALTHCARE TECHNOLOGY

TO ACKNOWLEDGE THE individual's perspective and to design in collaboration with future users is argued to be specifically important when developing technology to support in chronic disease management, as technology aims to be integrated to an individual's daily life and used over long periods of time (Ballegaard et al., 2008). From prior studies, Ballegaard and colleagues propose two guidelines when designing technology for healthcare. These are: a) Design for continuity and b) Design for understandability and learning related to daily life. Similarly Kilbourn and Buur (2007) advocate design of tools for enskilment, allowing for a sense of empowerment. In their article Kilbourn and Buur propose the view of the patient as a skilled self-care practitioner and that designers need to put emphasis on designing tools that allow for sense-making in a particular context, rather than designing machines that operate independently, alienated from human agency. The tools designed for enskilment should allow for growth as enskilment happens over time and hence allow for an integration of knowledge and experience. In today's context where measuring different factors in our bodies by using sensors and technology is seen as the dominant way of understanding health, the enskilment trajectory emphasize design for interpretation and sense-making as necessary in order for the individual to take appropriate action. (Kilbourn and Buur, 2007)

2.2.5. NEED FOR IMPROVED USER EXPERIENCE

As health applications and devices are gaining increased popularity at the consumer market, one can see a considerable gap in user experience between these and the products used in medical settings. A user's experience with an interactive product is affected by both the pragmatic and hedonic qualities of the product (Hassenzahl et al., 2010). Pragmatic qualities refers to do-goals, which enables fulfillment of a task (usability), and hedonic qualities refers to be-goals, how the product provides pleasure in use and ownership (to be admired or stimulated). We are not only using products because they are useful to us. The products that we own, and also services that we use, are part of our identity construction (Belk, 1988). Even if not necessary for task fulfillment, the hedonic qualities of a product, supporting the be-goals, are the main factors for a positive experience (Hassenzahl et al., 2010). John Zimmerman propose, that as an advance of user experience, there are opportunities to design interactive products that become explicit collaborators in a user's identity construction (Zimmerman, 2009). Product attachment can be created by making someone feel they are becoming the person they desire to be, in a specific role, through interaction with a product. If seen through the framework of Zimmerman, health and fitness applications in the consumer market offers identity construction and product attachment in several ways, such as role engagement, control of health status, and making long-term goals present in daily life.

In contrast, in design of medical devices and applications, pragmatic qualities such as functionality and usability have traditionally been in focus. These devices, which are designed for hospital contexts and the formal codes of such environments, are often perceived stigmatizing when used in other social contexts (Bispo and Branco, 2008). The standardized clinical design, does not offer personal identity construction, but can instead diminish it. In terms of assistive devices, stigma is often connected with a physical object, such as walking or hearing aids (Jacobson, 2010). However, one can see identity construction as an important matter for design even when it comes to interactive services. As in the case of Living Profiles, the teenagers wished for a personal health record to reflect their personal identity in order for them to use it (Chira et al., 2010).

To increase usage and attachment to products like Genia, aiming

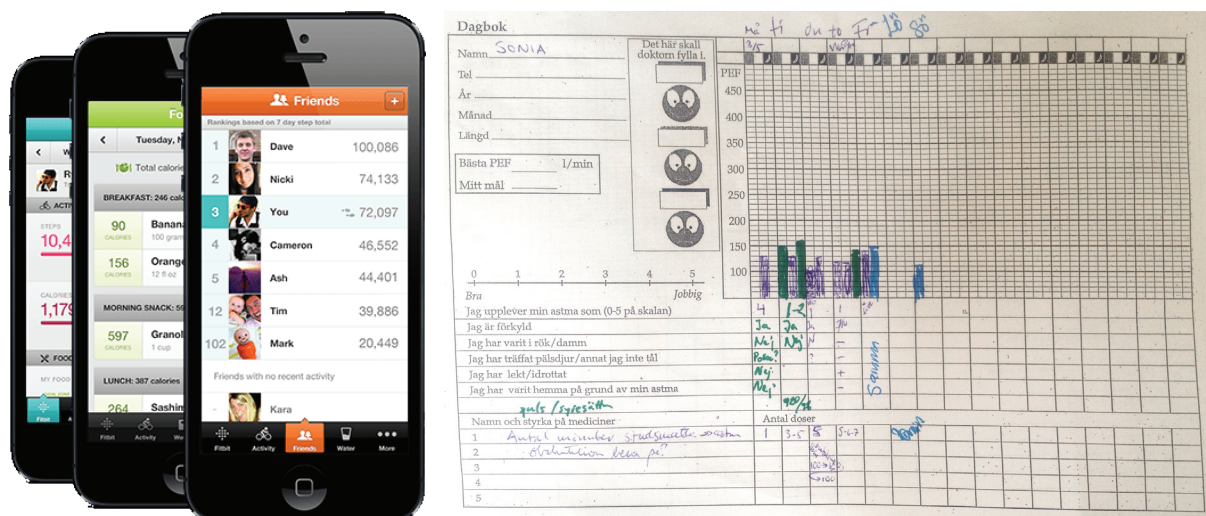


FIGURE 2.2

Example of the difference in user experience and tools for health management between the commercial market and the medical setting.

Left: Fitbit health application <http://www.fitbit.com/uk>
Right: Health journal used in swedish CF-care.

to bridge between healthcare setting and the personal sphere, one can see that focus need to be put on hedonic qualities for an improved user experience, which enables identity construction that look beyond the role of the patient, to the role of the individual.

2.2.6. MOTIVATION AND GAMIFICATION IN RELATION TO CHRONIC DISEASE MANAGEMENT

ADHERENCE TO TREATMENT for chronic disease is highly affected by the individual's own motivation. To be motivated means to be moved to do something (Ryan and Deci, 2000). In the case of chronic illness it would mean to be moved to change one's own behavior or to be moved to adhere to recommended treatment over time. The study of what affects behavioral change has been a key area of research within health psychology for decades. There are several social cognition models aiming to understand the determinants of behavior and behavior change (Conner and Norman, 2005). To provide an overview this extensive work is out of the scope of this thesis. However, in relation to CF, which is a genetic disease, the focus might not be on behavioral change per se, instead more interesting would be to understand the factors affecting motivation to treatment adherence. Therefore a brief overview will be given of the Self Determination Theory, a macro theory of human motivation and its application to healthcare.

Self Determination Theory

RESEARCH WITHIN THE field of psychology shows that people in general have different levels of motivation but also different orientations of motivation. The orientation of motivation is the underlying attitudes and goals that lead to action. Motivation has been conceptualized to be either intrinsic or extrinsic (Ryan and Deci, 2000). Intrinsic motivation is when the underlying reasons for action are internal, when doing something because of own interest. For example an artist who paints because it gives him pleasure or a student immersing in a book because of own interest in the topic. Extrinsic motivation is when the motivation for action is an outcome separate to the action itself, to do something or to avoid something because of an external reward or punishment. Taking the example with the artist and the student. If the artist would paint for the money received when selling the painting, or if the student would read in order to get a good grade in the course they would be driven by extrinsic motivation. Few of the activities that we perform daily are driven fully from intrinsic motivation; instead most of our actions are driven from different extrinsic motivations. According to the Self Determination Theory, extrinsic motivators can be divided into different types, depending on to what extent the motivation derive from one's self (Ryan and Deci, 2000). The level of internalization and self-determination is affected by social contextual conditions. Social contextual conditions that support one's basic psychological needs of competence, autonomy and relatedness are seen as the basis to facilitate internalization and self-determination (Ryan and Deci, 2000).

Research on motivation within the context of healthcare and well-being state the importance of internalization of values and skills for behavioral change to be performed and maintained (Ryan et al., 2008). Studies show that the self-determination theory applied in healthcare, where patients' psychological needs for autonomy, competence and relatedness are supported have positive outcomes of health, adherence and engagement to treatment (Ryan et al., 2008).

Hence, consideration to the user's psychological needs for autonomy, competence and relatedness can be seen as important factors when designing for user experience in the context of healthcare, and especially in the context of supporting self-management of chronic illness.



FIGURE 2.3
Fight cancer. A game aiming to support kids and young adults with cancer by giving players a sense of power and control and encourage adherence to treatment.
 Re-mission2 <http://www.re-mission2.org/#/page>

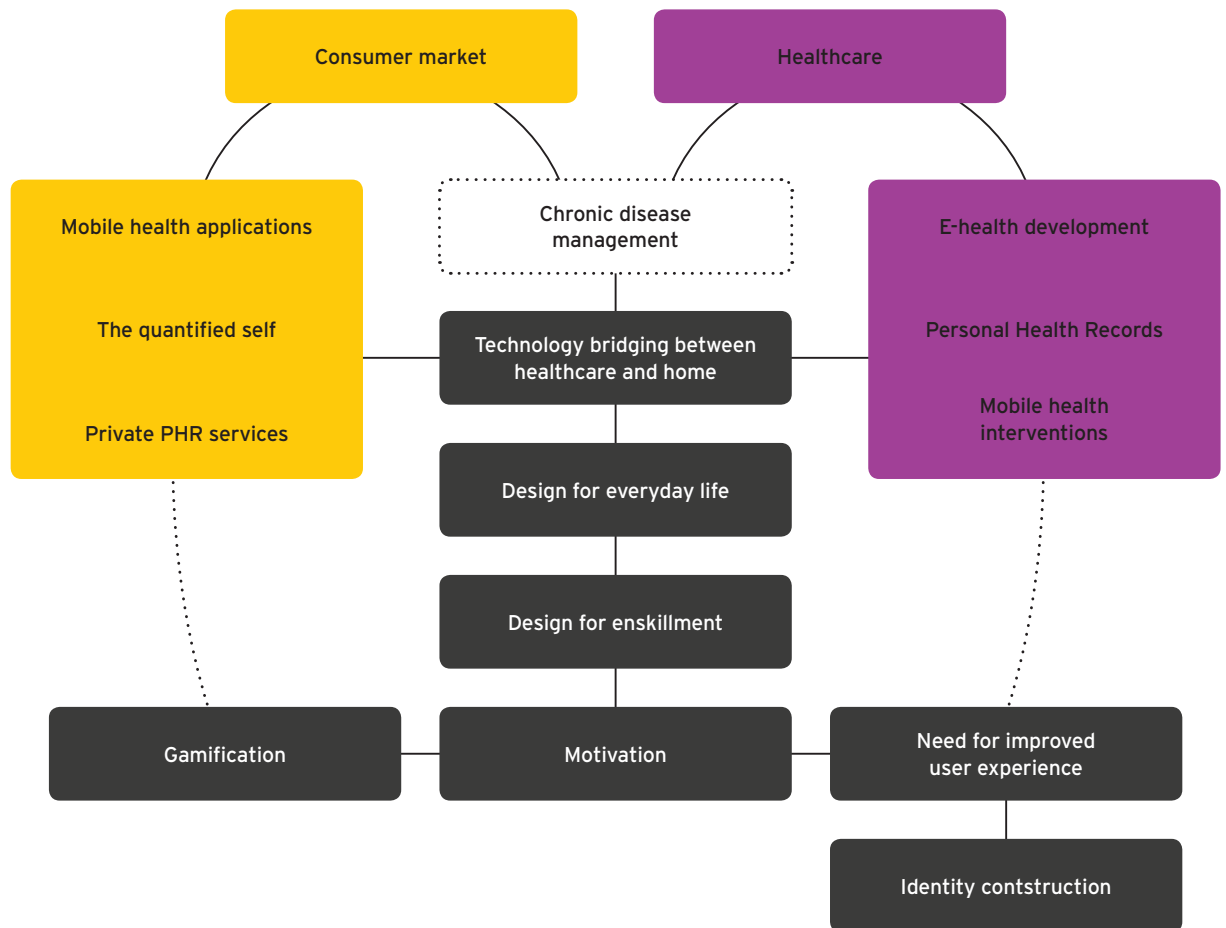
Gamification

OTHER THEORIES, FOCUSING motivation towards learning, distinguish several factors that promote intrinsic motivation in learning environments. These factors are: curiosity, control and fantasy (Malone and Lepper, 1987). Also interpersonal motivators are recognized to be competition, cooperation and recognition. Even though these theories focus more specifically on learning, they can be applied for health promotion as well (Ahtinen et al., 2009). The motivational factors presented above are common characteristics in games. The past few years a trend around gamification has grown in applications for in health promotion. Gamification is the use of game design elements in non-game contexts, such as applications or processes, as a way to engage and motivate users and to solve problems (Deterding et al., 2011). Many commercial applications for health and fitness promotion use elements of gamification in relation to self-tracking, such as rewards, short-term goals and elements of competition between users.

In addition to gamification, where elements from games are used in a non-game context, also pure games exist for health promotion, such as Nintendo Wii. Even games targeted for patients with chronic conditions is a growing concept. Although it does not seem realistic to plan for games that chronically ill will play for the rest of their life's, the use of games for health are seen to be useful in different periods of time, such period called adherence cliffs (Andersen, 2013). With the broadened use of games and gamification, a critique has been raised from game developers not to take gamification for a panacea. Rewards and badges are not automatically the solution to underlying problems. Careful consideration to how intrinsic motivation can be activated with use of extrinsic motivators is recommended when applying game elements to application and processes (Zichermann, 2011).

2.2.7. MOBILE HEALTH INTERVENTIONS

The potential of using mobile phones for professional health delivery is increasingly gaining awareness, especially to use mobile health applications for health interventions (Steinhubl et al., 2013). There are several examples of health interventions delivered through mobile phones that have shown positive outcomes both for chronic disease management and health behavior change (Klasnja and Pratt, 2012). The mobile phone offers a variety of opportunities for design and the device is seen as positive thanks to the often very personal nature of the device.



The mobile phone is often an essential part of an individual's daily routine, and a device that people have a positive emotional connection to. These aspects can reduce barriers to adoption and be positive for health interventions (Klasnja and Pratt, 2012).

Despite research showing positive outcomes, the adoption and implementation of mobile applications to the national healthcare system in Sweden is only starting to take place. A national infrastructure for integrating smartphone applications, as an official channel for interaction and data sharing between patient and healthcare provider, is not yet fully established, although initial trials are being developed. The mobile application which is in focus in this thesis project will be one of these piloting projects.

FIGURE 2.4
The different themes described in the text are here visualized in a map showing the connection between them in relation to chronic disease management.

3. CASE GENIA

Through the application of design methods this project seeks to find opportunities for a mobile application to support patients and families in daily life with cystic fibrosis, as well as in collaboration with care providers. The project has its starting point in an already existing application, Genia, and the project aims to, from identified opportunities, present a design concept for a next version of Genia. With the term concept, I here mean a proposal of direction for future development of the application.

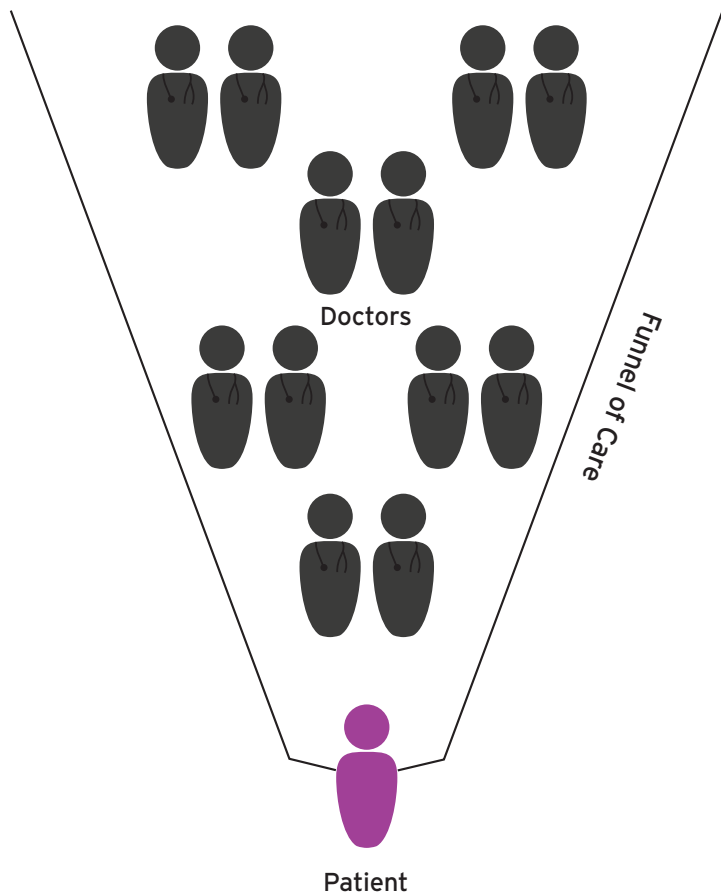
3.1. BACKGROUND

3.1.1. WHY GENIA CAME TO LIFE

IN THE LAST fifty years, care for chronic illness have gone from fairly clear and simple ways to interact between patient and professional (in a time when CF children did not get past childhood), to often quite complicated systems of care (with CF children growing to become old) (Batalden et al., 2006). Patients and families living with cystic fibrosis are today super users of funnels of care, interacting with teams of care providers.

Inspired by learning from scholars at the Dartmouth Institute, Andreas Hager who has a daughter with CF, saw the importance of facilitating for all the individuals in the clinical microsystem to work together, where patients and families could contribute and take a more qualified role in lessening the illness burden. For patients and families, this would require some biomedical knowledge, some understanding about the systems of professional care they meet and knowledge about the resources, and the social support available by

Collaborative Medicine



Traditional Medicine

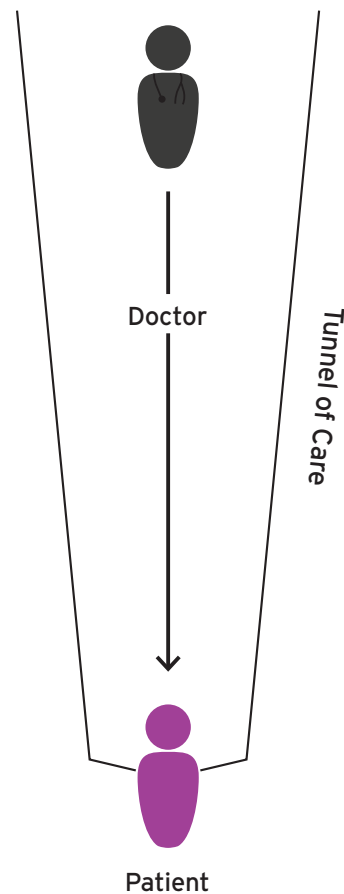


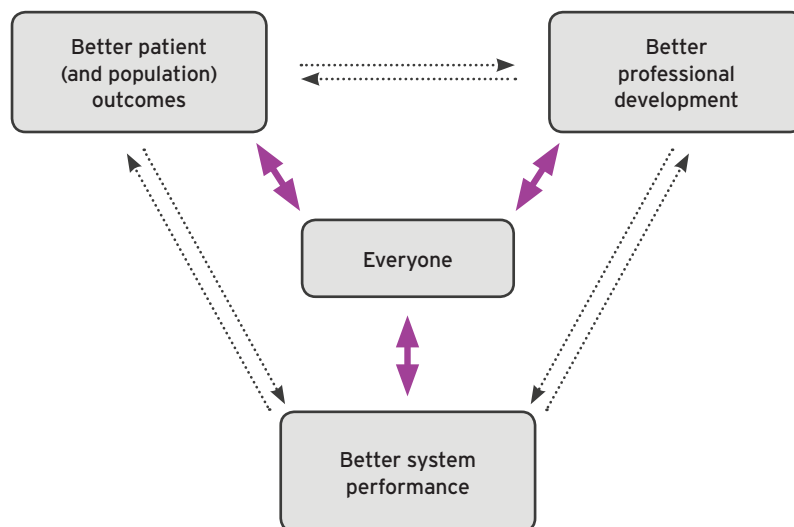
FIGURE 3.1
Interaction in care for chronic illness has changed from tunnels to funnels of care.

both patient and professionals.

The notion of all working together, combining the efforts of everyone, healthcare professionals, patients and their families, researchers, payers, planners and educators—is what Batalden and colleagues mean can lead to better patient outcomes (health), better system performance (care) and better professional development (learning) (Batalden and Davidoff, 2007).

Batalden also highlights the importance of building such collaborative care on competence:

”It is important to remain focused on ”competence” so that collabora-



tive care is "good" care. It has been demonstrated that patients' confidence in their self-care can increase while their competence has not." (P. Batalden 2013, pers. e-mail comm., 4 November)

The Genia application was a first try from the company Chimes, founded by Andreas Hager, to facilitate for patients and families to take a more informed role, and to catalyze new interaction between involved parties in the private and professional networks. With the understanding that care professionals do not heal, one aim with Genia was to support the collaborative efforts of everyone in removing barriers to healing, which occurs in the patient.

Chimes launched Genia 1.0 over AppStore in October 2012. However, it soon became evident that the Genia system had to find a way to better support the everyday work done by the families at home and, not the least, find a way to trigger the motivation and engagement amongst the children with CF, who were the main target, their health and wellbeing being the aim of everyone's combined efforts. This was a main reason for Chimes to search for an opportunity to employ design thinking in a second iteration of Genia.

"An important part of my mission is the creation of tools that can help learning, in-sighting and training in the personal sphere, and also help the expression from there to others, to achieve co-productive meetings. Genia 2.0 is an important step in this!"

ANDREAS HAGER

FIGURE 3.2
Linked aims of Improvement
adapted from BATALDEN, P. B.
& DAVIDOFF, F. 2007. What is
"quality improvement" and how
can it transform healthcare? *BMJ*
Quality and Safety 16, 2-3.

3.1.2. CYSTIC FIBROSIS

THE INTRODUCTION TO this thesis gave a short description of cystic fibrosis (CF) as a diagnosis. Below follows a somewhat more comprehensive description about life with CF to provide context for the project.

As previously mentioned, CF is an autosomal recessive disease, caused by a gene mutation. The disease has been known since the Middle Ages, though it was not until the 1930's that the whole spectrum of the disease was detected. Today, individuals with CF are often diagnosed in their first year of life and extensive treatment is crucial for long-term survival. Living with CF puts high demands on the patients and their families. Self-management consists of burdensome treatment that can take up to two hours everyday of respiratory and physical exercise. The respiratory symptoms are often the most severe, however since CF affects all the glands in the body, it also causes problems in the digestive system with challenges to assimilate food as a consequence. Often, CF is said to be a lung, liver and digestive system disease, but there are many more implications to it. (Vårdguiden, 2013, Socialstyrelsen, 2013)

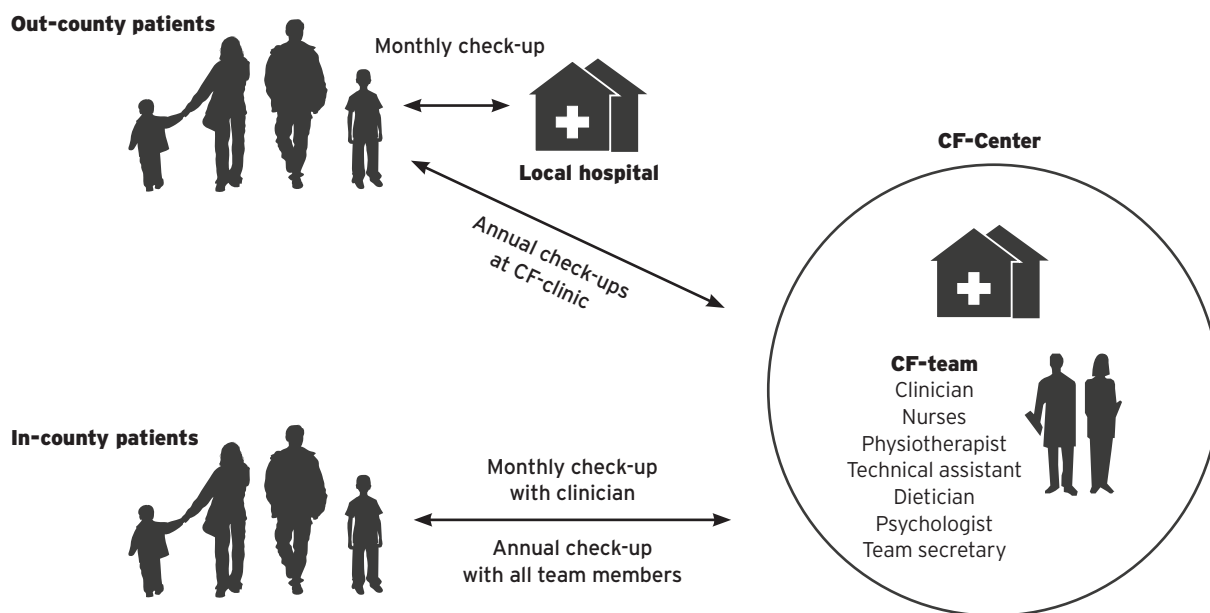
When having cystic fibrosis it is important to treat bacteria before reaching the lower airways; therefore, antibiotics are given generously, even if showing symptoms of a common cold. CF patients are recommended to avoid unnecessary exposure of bacteria, which naturally impacts daily life in various ways.(Vårdguiden, 2013)

EFFECTS OF RESPIRATORY treatment or non-adherence to treatment are often deferred. This can cause doubts of the necessity of treatment amongst patients and affect adherence, especially amongst adolescents (Bucks et al., 2009). Patients with CF and their care providers face many obstacles including uncertainty of best therapies, in relation to a high treatment burden. This challenge is estimated to grow, since new treatments become available and there is a challenge to determine the best application of different treatments and at the same time balancing treatment burden with quality of life (Zemanick et al., 2010).

In Sweden the total cost of care for a CF patient is estimated to be in average €22 000 per year, not counting costs for medical devices and transplantations. Since the population is relatively small (600 patients), it has been difficult for care professionals to work from 'evidence based medicine', where evidence from previous data manifest best practice of treatment for individual patients. In addition, new drugs are under

development, which could potentially imply a cure for some CF-patients. These drugs are very expensive (over €200 000 / patient/year) and the new treatments need both clinical and health economic evaluation.

Hence, continuous systematic monitoring and evaluation of health data is needed in order to improve outcomes of care as well as individual treatment plans. Without such follow-up, there is a risk for inequality of care, not reaching the goal of providing best individual treatment for all CF patients, and hence not continued increased survival. (Lands-tinget i Östergötland, 2013)



3.1.3. SWEDISH CF-CLINICS

SWEDISH CF-PATIENTS visit the hospital regularly. Every 4th to 6th week there is a consultation at the clinic (the so-called monthly check-ups). In Sweden there are four specialist CF-centers, one each in Stockholm, Lund, Göteborg and in Uppsala. Patients living nearby a specialist center complete the monthly check-ups at a CF-center. Out-of-county patients (Sw. utomlänspatienter) complete the monthly check-ups at their local hospital and attend to one more thorough annual consultation at a CF-center. Since the diagnosis puts high demands on the patient and the family it is important to provide both medical, social and psychological support. The teams at the CF-centers comprise professional roles from all these fields to provide the support needed for the patients.

FIGURE 3.3
Overview of how Swedish CF-patients regularly meet professional care providers, and at least once a year a specialist CF-team.

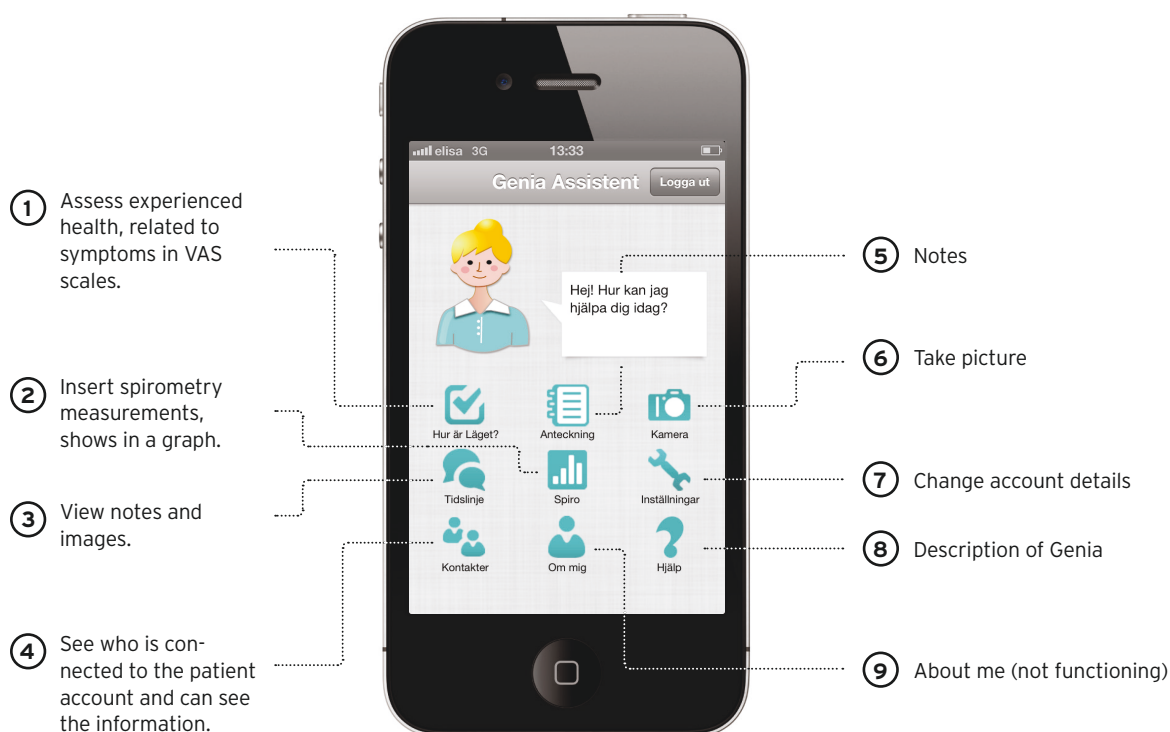


FIGURE 3.4
Description of the existing
Genia application.

ABOVE: Overview of
functionality.

RIGHT PAGE: More Detailed
description of the different
functions.

3.1.4. DESCRIPTION OF GENIA

GENIA IS A smartphone application targeted towards children with cystic fibrosis and their families. The application is meant to facilitate collection and storage of personal observations about life, illness and health at home, and sharing of information to the care team before the clinical visit. The need of such application came from families' own long-term experiences about difficulties in figuring out disease symptoms and deciding on right and best individual treatment. Genia was launched as a way to improve the monthly meetings at the CF clinic, helping clinicians to be more informed by the patient's experience of health and about the patient's situation in life.

The application that was released on App store in October 2012 was developed at the personal initiative of Andreas Hager, who has a daughter with CF, and Tobias Öhman who is an entrepreneur in information technology development. For further description of Genia, see Appendix.



①

DAILY HEALTH ASSESSMENT

VAS scales for symptoms

Result is summarized to a percentage value.

0%= Good health

100%= Worst case



②

SPIROMETRY

Spirometry measurements can be added and displayed in a graph.



③

OVERVIEW OF DATA

Health assessment, own notes and images are displayed in a timeline.

3.1.5. DESIGN CHALLENGE

EVEN THOUGH THE development of the existing product was user driven, Genia was not being adopted to any higher extent by other patients and families. There was a need to find motivations and needs within the targeted user group in order to find opportunities for design in the next iteration of the application. As a piloting project there is a possibility for Genia to be directly connected to the swedish national ehealth service system. Hence further understanding for what such integration could entail to benefit both patients and professional care providers was required. The hypothesis in this thesis is that design methodology could provide insights and support to answer these challenges. The project in this thesis aims to give suggestions to further development of Genia and present a concept for design of the application.

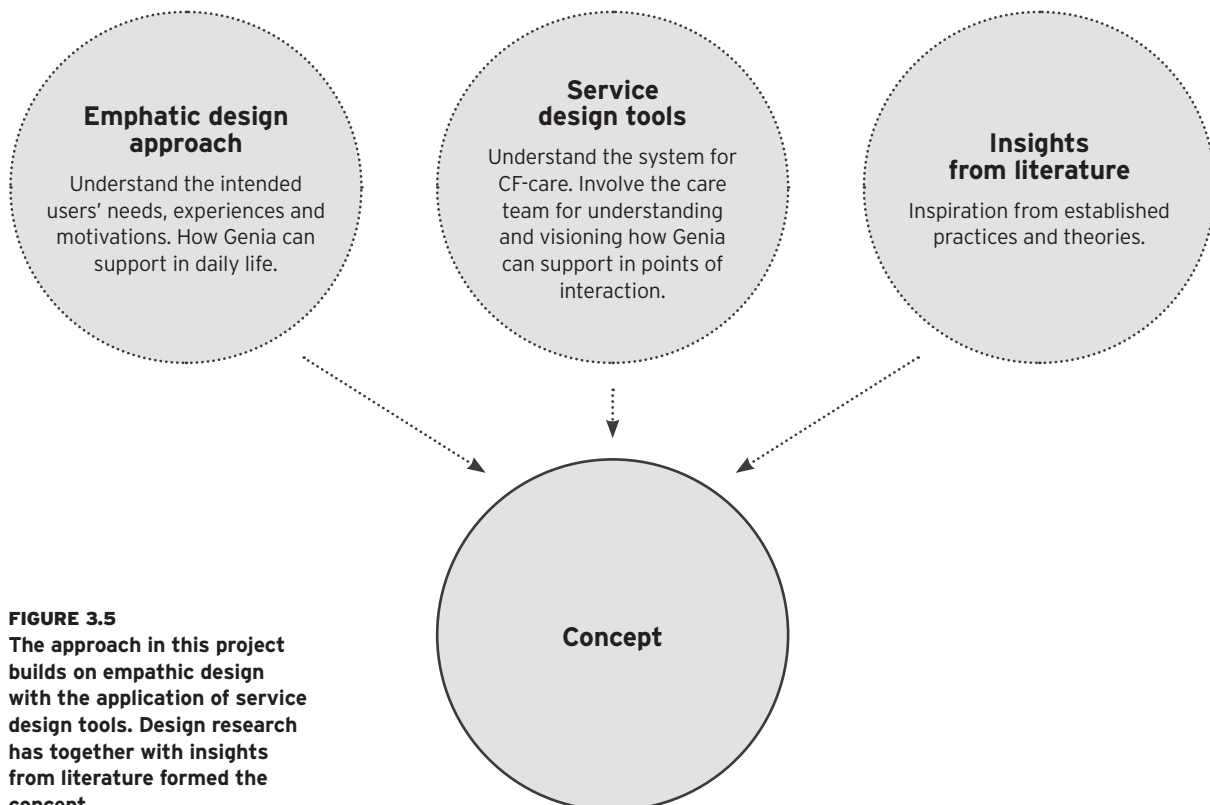


FIGURE 3.5
The approach in this project builds on empathic design with the application of service design tools. Design research has together with insights from literature formed the concept.

3.1.6. DESIGN PROCESS OVERVIEW

Empathic design

THE IMPORTANCE OF user centered design research, to understand users daily practices, needs and preferences, have become evident in prior projects when designing and implementing new technology in the healthcare context, where designers are not able to draw from own experiences (Hyysalo, 2004). A key factor in failure of innovations has shown to be the lack of such understanding, which have been especially problematic the ICT industry where many innovations are driven from the development of technology (Steen, 2011).

In this particular case, when designing for a target group with a specific chronic illness, thorough human centered design research was seen as vital since the author had no personal experience to draw from. I have primarily taken the approach of empathic design which focuses on understanding and empathizing with peoples experiences to seek insights, practices and problems, in order to find opportunities for design (Mattelmäki et al., 2014). In the process for emphatic design the findings are analyzed and becomes the starting point for ideation and prototyping of possible solutions (Steen, 2011). In my process I have also included elements of co-design where users are encouraged to bring ideas into the design concept (Sanders and Stappers, 2008). Elements of co-design have also been applied with the aim to understand current practices.

Even though the target group for Genia was stated to be children and families, research have been carried out with several age groups of patients, since I found it necessary to gain these perspectives in order to inform design decisions.

Service Design

WHEN IMPLEMENTING NEW technology in healthcare it has also shown essential not only to meet the needs of the immediate user, but the interests and motivations of the secondary users (such as nurses, clinicians and relatives), all the roles that are involved in the activities influenced by the new technology (Hyysalo, 2004, Aarhus et al., 2009, Patricia Flatley Brennan, 2010). Hyysalo introduces the term; network of utilization, to describe how technology needs to transform and connect linkages between a network of people and artifacts.

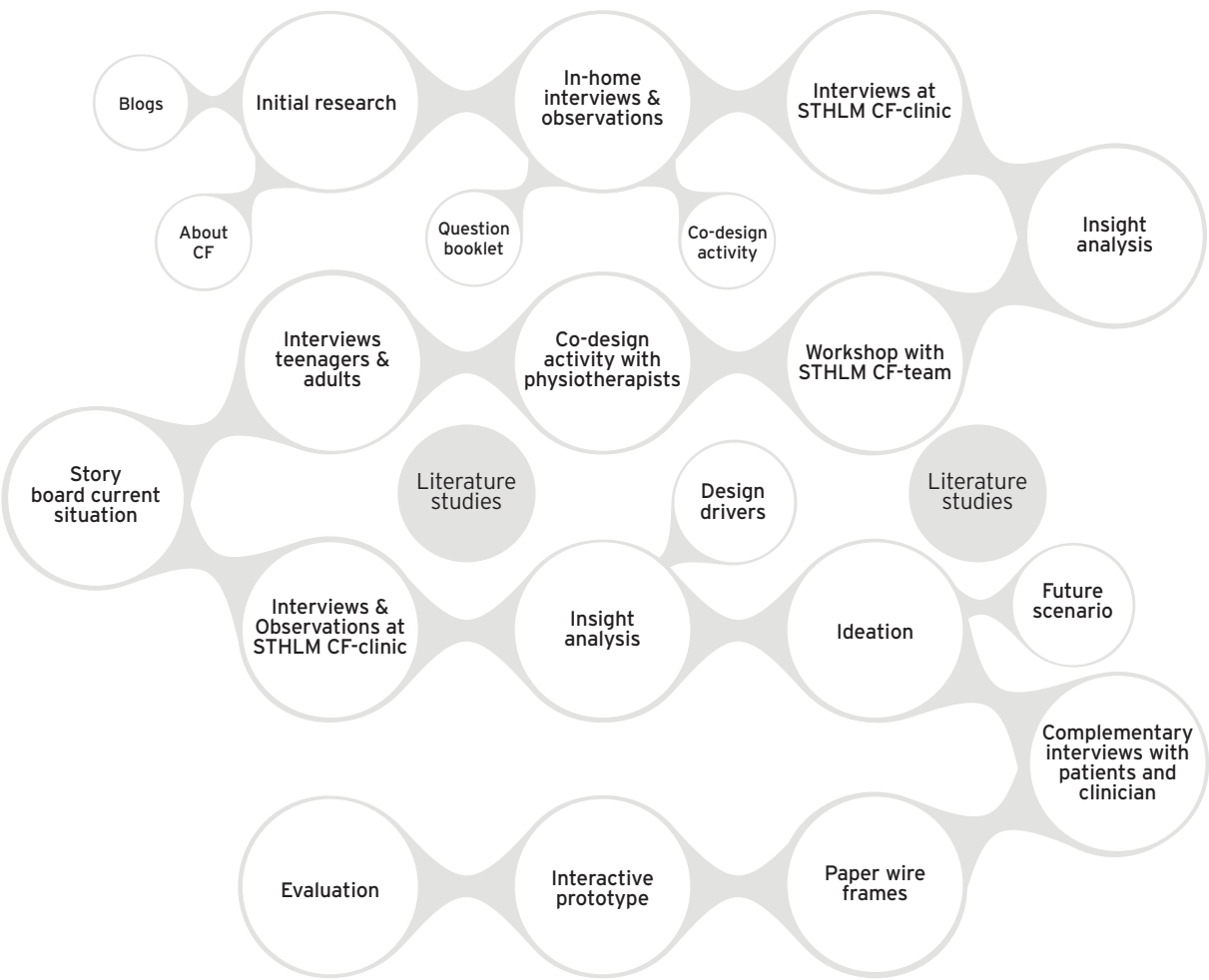
”A successful network of utilization is thus based on nurturing and and creating couplings that can be tolerated by all the involved parties.” (Hyysalo, 2004: 224)

In order to understand the system of CF-care, the involved stakeholders and what role Genia can have in this system, methods from the field of service design have been applied. Service Design offers tools to gain a holistic view for design and have been used when searching for opportunities in how Genia can support in points of interaction between involved parties.

Insights from literature

THE LITERATURE REVIEW has provided a base for understanding of practices and theories relating to chronic disease management and IT in healthcare. Insights from literature have functioned as guidance and inspiration in design of the concept.

FIGURE 3.6
The design process with activities visualized chronologically.



3.2. DESIGN RESEARCH

This section describes the human centered design research, conducted with patients and families living with cystic fibrosis as well as with professional healthcare providers at the CF-clinic in Stockholm.

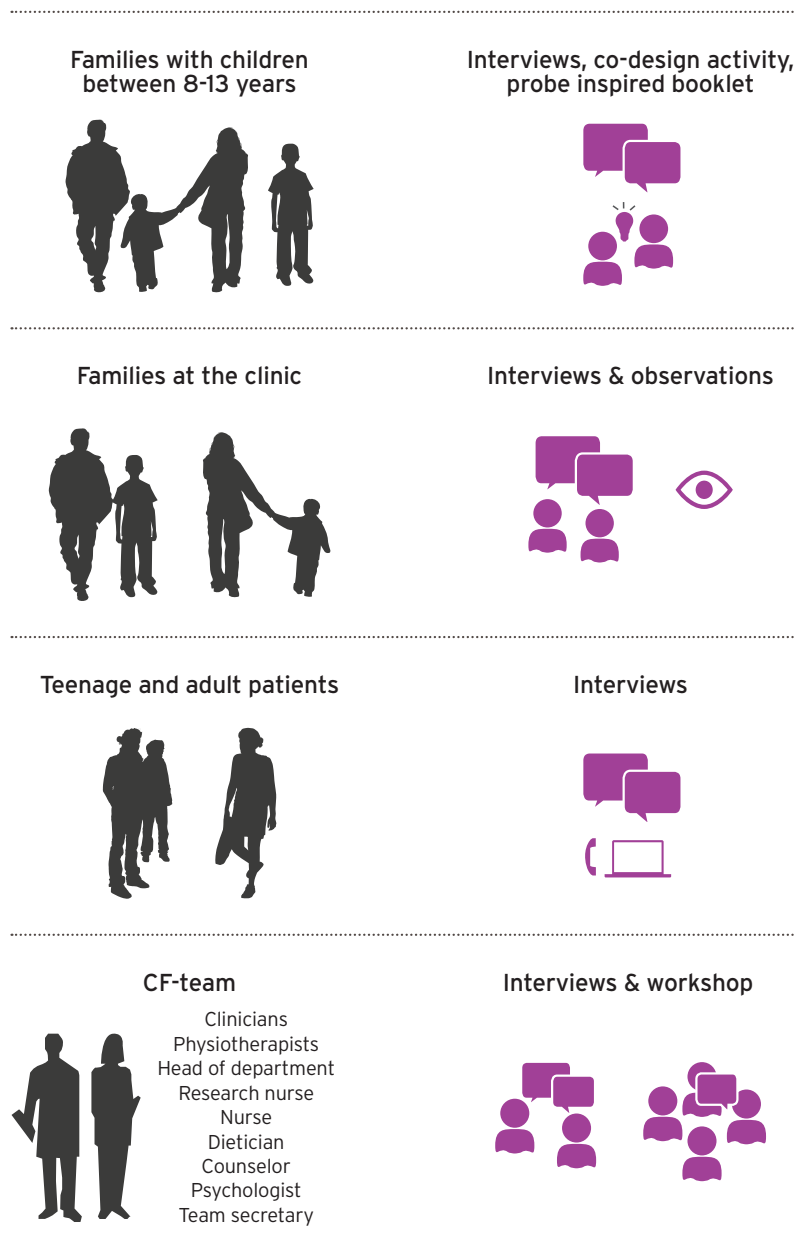


FIGURE 3.7
Participants in design research and the different methods used.

3.2.1. TUNING IN

AT THE START of the user centered design process it can be useful to gain some initial understanding for the area of design, or to map out what is already known, in order to plan for further research (Mattelmäki, 2006). In this so called tuning process to the empathic design research, I read blogs on the Internet written by individuals with cystic fibrosis. I found many blogs where people share quite personal experiences about their everyday life with disease. Reading these blogs was a useful and efficient way to get initial insight on the subject of peoples experiences when living with CF. From the blogs I got an understanding for how the disease can vary in severity and different perspectives on how daily life is affected. I do not discuss these findings in detail since they are not the foundation in my research, however later in my process I found many connecting points from what the participants in my research experienced and what had been found in the blogs.

3.2.2. LIVING WITH CF - VIEWS FROM FAMILIES AND CHILDREN

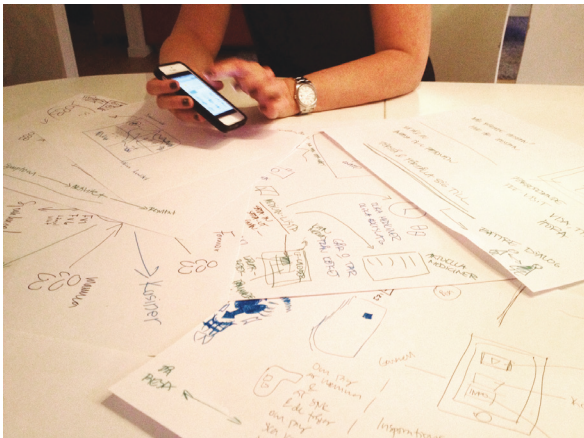


FIGURE 3.8
Interview using visual
material.

SINCE THE TARGET group for Genia was seen to be children and their families, user research was conducted by the author with five families, who have children with cystic fibrosis. The children's age varied between 8-13 years. Semi structured interviews were conducted, to obtain an understanding for how CF affects daily life and how one manages with the daily routines concerning medicine and treatment, as well as how the interaction with the healthcare team is perceived. The goal was also to find needs and motivation amongst these families that could reveal opportunities for design of the application.

The families participating in the user research had previously been informed about the Genia application through CF-patient networks or personal contact with Andreas Hager. Hence the Genia application was part of the discussion in the interviews to get an understanding for experience of use and incremental design opportunities, however, the aim was to have an open ended dialogue about personal experiences in

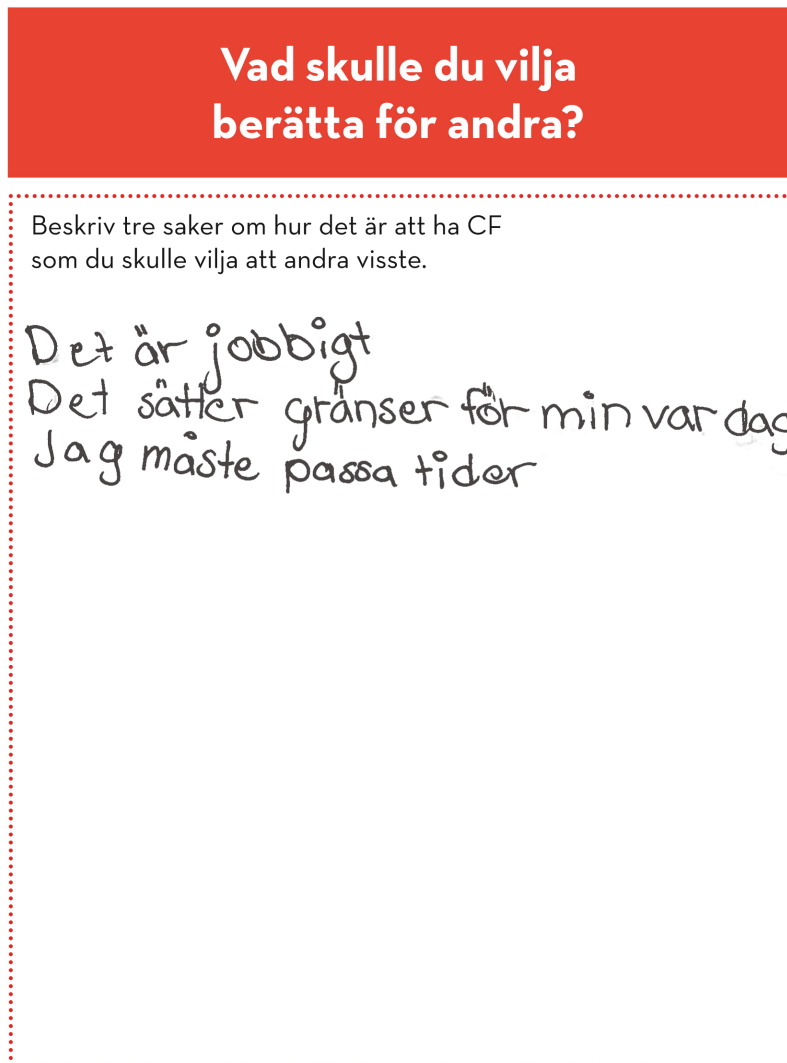


FIGURE 3.9
A page from a child's booklet, saying that life with CF is difficult and sets limits in daily life.

managing CF in daily life and interaction with the healthcare team to reveal opportunities for design. User stories can reveal opportunities for design that can be missed if only focusing on problems. Hence it can be beneficial to focus on both positive and negative perspectives. (Kankainen et al., 2012) Tangible material in terms of ideation cards and drawing material was used in the interviews, as co-design tools, since I wished to facilitate for the participants to share own ideas and thoughts.

The interviews were carried out in the families' homes since it is often easier to speak open and freely in a relaxed environment. The context of the home was also seen as appropriate for interviews

FIGURE 3.10
Home storage of medication.



FIGURE 3.11
Storage of medical
information.



since much of the daily treatment is taking place at home. The interviews were held with children and parents together. In addition to these interviews I also had the possibility to meet and talk to a couple of the children without their parents. I sought to hear the children's thoughts and opinions, unaffected by their parents' perceptions.

Since how people handle and experience life with disease is quite personal, I was unsure of how openly the children and parents would share their views and experiences. For the children to express their thoughts I designed a booklet, with questions the children could answer on their own, in their own time (see Figure 3.9). The intention was to get to know more about the children's view on living with disease, and how hospital visits were perceived. The children were invited to draw or add pictures in addition to writing their answers. This way for self documentation and reflection relates to the methodology of design probes (Mattelmäki, 2006).

Result

The interviews show that perspectives on disease management and motivations for using a mobile application differ between children and their parents. The findings are structured in two different sections, separating the children's and parents' perspectives.

Need for structure and sense of control

I UNDERSTAND THAT parents take most responsibility for disease management when the children are in this age. Being a CF-parent there are many things to keep track of, apart from motivating the child to follow daily treatment in terms of making sure meds are taken and that the daily exercise is followed, there are many practical concerns that need to be dealt with. The home storage of medications needs to be refilled, inhalation equipment needs to be constantly maintained and information of new treatment regimes needs to be shared with others such as school staff etc. I find that each family has their own strategies for making daily life as fluent as possible.

”It’s like putting pieces of a puzzle together with the doctor.”

Observations in daily life

OBSERVATIONS OF symptoms in daily life are seen as important, since signs of infection or health deterioration perhaps need to be taken action on, or reported to the healthcare team to adapt further treatment. One mother expressed it like “putting together pieces of a puzzle together with the clinician”. Sharing own observations provides support for the clinicians in planning further treatment. Parents express difficulties in keeping a structure for these observations. Today post-it notes and calendars are used to note down reflections or questions to bring to the next clinical visit. The need to note things down becomes evident. “One week later you have forgotten what it was you were to remember for the monthly control.”

Apart from observations and questions, parents also note down when antibiotics are used and what kind, to report to the clinician at the next visit. Antibiotics are often started at home, after a phone consultation with the nurse at the clinic, however this information doesn’t always reach the clinician. To keep notes about when antibiotics are taken is therefore seen as important in order to make a follow up with the clinician at the monthly visit. My interviews reveal a need for documentation of symptoms and antibiotics to gain a sense of control. “Sometimes it doesn’t feel like they have an overview” . A matter raised in several families is the difficulty to see and understand disease patterns over time, a visual overview of health state overtime was discussed as something that could be helpful.

The use of the phone for notes and observations is seen as positive, since “you always have it with you”, and it brings the possibility to make notes in the moment when symptoms become evident.

Interaction with care providers

IN GENERAL THE contact with the care team is seen as very good. All families were very appreciative towards the care their children get. However, parents express a wish for better follow-up on certain matters, such as test result and treatment. Several parents feel a need to be strong and push certain questions in order for action to be taken. When it comes to practicalities in reaching the CF-team over the phone, it is not seen as troublesome, but as something that could be made easier. E-mail is not a secure channel for patient information, and therefore the phone used to contact the care team in between visits. However, the clinic seldom answers the phone. "One leaves a message and they call back later or the following day." Some matters are essential to discuss in person, however other smaller issues could perhaps be dealt with more efficiently.

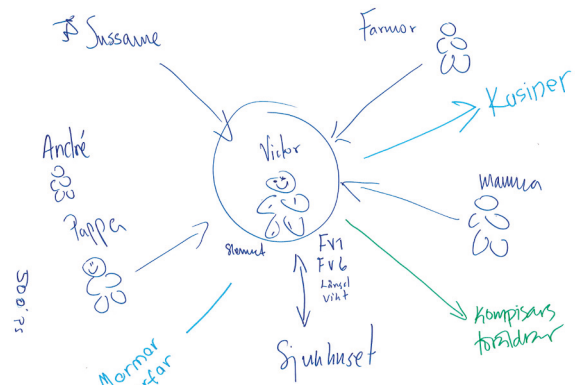


FIGURE 3.12
Drawing by a family of the people involved in care management.

Children's perception of daily life with disease - it can be both bothersome and positive

CF IS A genetic disease, hence, for the children a life with CF is the only life they know. CF routines are a natural, but a sometimes bothersome part of daily life. The children are very physically active, since physical exercise is part of the treatment regime. The physical activity is often perceived fun when it consists of sport-activities in the free time. Several children point out that living with CF has positive benefits. Such as being fit and sporty, and sometimes they perceive having a better health than their friends. What is seen as bothersome part of treatment is foremost the respiratory exercise since it is boring and can take long time. This part of the treatment is experienced as a hinder in their daily life, e.g. having to be home at certain times to do treatment instead of being with friends. Nagging from parents about treatment is also experienced annoying.

To explain for others why taking medication or eating special food and the feeling being

FIGURE 3.13
Interview using tangible material. One girl describing her personal network and what is shared between different people.

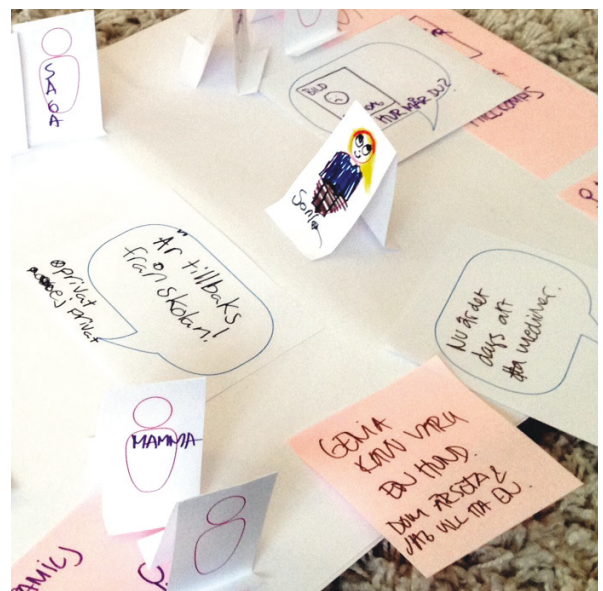




FIGURE 3.14
One girl showing me her medications and explains what strategies she has to remember to take them (picture used with consent from the family).

“different” when having a disease that doesn’t show on the outside is experienced annoying. The children wish that more people would know about CF.

The parents’ need of keeping track of symptoms was not expressed by the children. Instead it could be seen as bothersome to reflect over the personal health state too much. “I have other things to think about, such as homework and stuff.” “I’m bad at noting things down” When discussing a visual overview of health data that parents saw as helpful to understand the disease, the children also perceived it positive, but only if the results were good. “I like curves, but I only like when they go up of course”. When talking about learning more about the individual health one girl said “I don’t want to know what all my meds are for. If I would know maybe that would be on my mind all the time”.

Not all children I meet have their own smart phone, but the older

”I like curves, but I only like when they go up of course”

ones have. When discussing a smartphone application, the children see a more social function than their parents. One reason for this might be that children mostly use mobile applications for social interaction. When asking about what favorite apps they use they all mention applications with social functions such as Instagram and Kik. Some children express an interest to know more about others with CF. CF patients are recommended not to meet with other CF patients since there is risk for cross infection. However others said it would be unnatural for them to interact with other children just because of their CF.

Children perceive going to the monthly consultation at the clinic as a normal day, but at the hospital. “They are nice” “Mom is the one who do most of the talking” “Sometimes they say things I have to listen to and take in, and some times they are happy and tell me to continue what I do”.

Summary of findings

THE INTERVIEWS WITH the families showed that treatment burden can be bothersome for the children and cause annoying nagging from the parents. Most practicalities related to disease management are performed by their parents, who also take responsibility to ensure that treatment is followed by their children in this specific age. The parents have a strong role in the medical visits, at least within the age group of children and young adolescents. Amongst parents there is a need for structure of information related to disease management, such as observations of symptoms, questions regarding treatment and when antibiotics are taken. Being better informed is seen as something that could strengthen the collaboration with the care team and give their child a better care. Howe-

ver, for the children, reflecting upon their health and experienced symptoms could be perceived as burdensome when their focus lies on going through the treatment they are obliged to do everyday. The children's aim is to live their life with as little influence as possible from their disease.

3.2.3. PERCEPTIONS OF THE APPLICATION TODAY

ONE OF THE families used the existing application, the others had not tried it, which was stated to be due to usability issues, such as problems logging in and creating an account. The application is meant to be targeted foremost towards children, however the reaction I got from the children was that it seemed more for adults than for children in its look and feel. The findings from my interviews also incline that the functionalities in the application primarily support the needs of the parents and not the children. The existing application puts focus on health assessment in regards to CF-specific symptoms, through questions answered on VAS (visual analogue scale) scales. An issue discovered with these questions is that they might not relate to the personal health experience. CF mostly affects the lungs but in the day-to-day life the experienced symptoms can be stomach ache or other symptoms, which can make the questions feel irrelevant to answer. The importance of being able to customize the application to individual needs, depending on the personal health, was pointed out by the parents.

In the family who had used the application it was only the parents who used it, their daughter was only eight years old and did not have a smartphone. The parents did not use the symptom scales, instead they used the functionality of making free notes to note down symptoms or when taken antibiotics. The parents experienced the application to be a support when going to clinical visits, being better prepared to answer the questions from the clinician. The parents had also e-mailed information to the clinic through the app before one monthly check-up, yet they understood that the nurse was not familiar with receiving information in this manner, and had problems interpreting the data. When showing data of respiratory function taken at home to the doctor, the family did not get any response. In the interview the parents expressed the importance to incorporate the healthcare team in further development of the application in order for the application to be used to its full potential.



3.2.4. INTERVIEWS & OBSERVATIONS AT THE CLINIC

SHORT INTERVIEWS WERE held with patients and families in the waiting room at the CF-clinic in Stockholm. These were seen as a complement to the more in depth interviews previously made with families, both to get insights in a different context, but also to get the perspective from a different demographic group.

Having a newly diagnosed child

WHEN I'M AT the clinic I meet families who have younger children that are between 1 and 4 years old. I talk with them how they perceive daily life and what difficulties they face. Our conversation reveals worries of their child's health and stress about wanting to do things right. The parents feel that there are so many things to keep track of, such as medication doses, doctors appointments and physiotherapy. All information that is received from the clinic can be difficult to grasp. One woman has a whiteboard at home where she puts all different kinds of information and documents related to her daughter's CF. We talk about the use of a smartphone application and she says she would have great usage of a tool to help her remember appointments, medication dosages and keeping notes of treatment.

FIGURE 3.15
LEFT: Clowns
visiting the clinic

**RIGHT: A girl meeting
the physiotherapist
at the clinic.**

Strategies for self-management develops over time

IN COMPARISON TO the families I had previously met, parents with younger children do not have the same established routines for self-management. An application could therefore be a support in a different way, in helping with daily tasks such as giving the right dosage of medication, that for others have become a routine.

3.2.5. PERSPECTIVES ON BEING A TEENAGER WITH CF

When children are young, the parents take most of the responsibility to ensure treatment is followed and for other practical issues. With age increases also the own responsibility for managing the disease. The intensive treatment can be very burdensome and adolescence is a recognized problematic period in CF-care, often with poor adherence to recommended treatment. Hence it was of interests to get the view from older patients than the children interviewed previously, especially if the application would be used over several years, from late childhood to adolescence. Through a blog on the Internet I got in contact with two girls, 13 and 15 years old, who have CF. Two Skype sessions were carried out with semi-structured interviews around perceptions of managing daily life with disease, perceived difficulties, and their relationship with parents and healthcare providers.

Becoming independent

THE INTERVIEWS SHOWED that the girls have started taking more responsibility in managing their disease. However they feel that their parents have a huge need of control. “It’s easy to say yes, when mom or dad asks if I’ve taken my meds, even if I haven’t because I know how upset they get”. “It’s not that I don’t want to follow my treatment, I just forget or I’m being lazy”

In discussion about a smartphone application for CF patients the girls saw opportunity in getting inspiration and motivation for daily exercise as well as help to remember medications. “It might be easier to be honest to the phone since it doesn’t judge you”

The girls also brought up the social aspect when talking about a smartphone application. One of the girls used Instagram to keep in contact with other CF patients all over the world. She felt it gave her strength and that only other people with CF could fully understand her. The girls also expressed that it would be positive if the app could be

personalized to individual interests and needs. “Some periods it might be meds you want to get reminders of, and other times there might be a need to track respiratory function.”

Reflections on the clinical visit

WHEN DISCUSSING MEDICAL visits they both express how difficult it is to answer the question “How are you”. The question is perceived very difficult to answer, especially at the annual consultation, since how one feels can vary very much over a period of time. These girls are out-county patients which means they visit a CF-clinic once a year, while the monthly check-ups are performed at the local hospital.

“At the annual consultation one is supposed to remember all that has happened during the year. It is difficult to summarize a whole year with CF to a doctor in one hour”

To the question how a good doctor’s visit would be, the answer was: “A good visit would be that the doctors understand what happens at home, and prescribe treatment from what actually happens, and not only from what one tells them.”

Need for privacy?

THE FUNCTIONALITY OF the existing application was described briefly, and how several people can use it, connected to one account. The girls saw positive aspects of this, such as getting help in noting things down, or to share information between divorced parents. However, the girls noted that they might want to keep some data private, and not shared with parents.

Summary of findings

BECOMING A TEENAGER means taking more responsibility for disease management and a tool for reminders and motivation is perceived to be useful. To be able to express health state over time is perceived difficult, but as something that could perhaps improve the doctor’s visit. If an app is used of teenagers and their parents together there might be issues concerning privacy arising.

3.2.6. LOOKING BACK - REFLECTIONS ON GROWING UP WITH CF

I WAS ALSO interested in hearing how older patients perceived growing up with CF, since I believed these reflections and experiences

could provide insights for how an application could assist children in daily life. Through the nurse at the CF-clinic and Andreas Hager I got in contact with a group of older patients between 20 and 30 years who lives in different places in Sweden. I was interested to know how they experienced adolescence with CF and how they manage their disease today. What cues do they have to sense their state of health? The interviews were conducted over the phone.

Growing up with CF

THE STORIES SHARED from older patients reflect quite well what the children and teenage girls shared about the parents' need of control. When growing up, nagging from parents was annoying, but needed. One person tells me how he occasionally skipped treatment but then lied about it to his parents, to avoid trouble. Especially the respiratory exercise was seen as burdensome. "No friends had to do it so I thought why should I?" One girl remembered her mom letting her go by her self to the doctors' appointment when she was 13 years old. She remembered being angry at her mom for not coming along with her. Looking back she is now happy that her mom made the decision of letting her go by herself, since she has understood that other patients have difficulties becoming independent from their parents.

Strategies for self-management

THE INTERVIEWS REVEAL different personal strategies for self-management that the individuals had when growing up. These strategies emerged during the teenage years, when starting to take more own responsibility. One person had when he was 12 years old, been triggered by seeing the graph of his pulmonary function at the yearly check-up and this became his motivation to continue treatment. His goal was that it would not decrease until next year.

Another strategy was to put up short-term goals for treatment adherence to reach. Examples of such goals were "the following two weeks I will eat a healthy breakfast" or "I will focus on this respiratory technique for the coming week and do it well".

For another person it wasn't until he realized that the treatment made him feel better that he really put focus to adhere to it. He realized that if he followed treatment he was able to participate in more activities in his free time, and that was his motivation.

Health cues

TODAY THESE INDIVIDUALS attend to different cues in their health that tells them if they might need antibiotics or increase the daily respiratory exercise. Examples of such cues are more cough than usual, tiredness, changing color of mucus or that inhalation takes longer than usual. If needed they contact the care team for advice, sometimes it is only some motivation or calming words that are needed, and the antibiotics can wait.

A need to note down courses of antibiotics is expressed, to keep track of what different kinds are taken and how many courses of treatment that are taken during the year. There is a fear to become resistant towards certain antibiotics and therefore it is important that the kinds of antibiotics vary.

Also from this age group it's expressed to be difficult to answer the question "How are you", at the clinical visit. "It is difficult to answer, I sometimes get blank and don't remember really how it's been". Some prepare for the doctor's visit with notes of things they want to discuss, or to remember practical issues that needs to be dealt with.

Contact with the care team

IT IS EXPERIENCED quite troublesome reach the care providers, especially if being an out-county patient. Here is one story from a person living in the far north of Sweden, where there is no clinic close by. "The clinic didn't answer on the phone, so I sent them an e-mail. They didn't reply on my e-mail either, so I had to ask my mom, who lives closer to the clinic to go over there and ask if the had received my e-mail."

Another story goes: "I had to book a doctors' appointment for a small practical issue that easily could have been dealt with in a more efficient way".

Summary

THE RESPIRATORY EXERCISE was perceived as burdensome growing up, which could result in occasionally skipping treatment. Personal strategies for motivation to treatment adherence was developed, that could inspire directions for design of an application for children and adolescents. To get in contact with the care team is experienced troublesome and could be more efficient. Even older patients experience a difficulty in expressing how they perceive their health to be, and a tool for keeping track of antibiotics is perceived as something that could be useful.

3.2.7. PERSPECTIVES FROM CARE PROFESSIONALS

INVOLVEMENT FROM THE healthcare team in design of the first version of Genia had been quite limited and I saw the need to put effort in researching the context of the application from a healthcare perspective. The research would need to consider the system level, e.g. understand how Genia could be integrated in the healthcare's e-service system, but foremost focus on finding opportunities for design in how Genia could bridge between the patient and the healthcare context. This section describes the research conducted in the healthcare context.

Interviews and observations

RESEARCH IN TERMS of interviews and observations were conducted at the CF-clinic in Stockholm to get an understanding for the healthcare context and the functions of the different roles in the care team. This understanding was necessary from my part in order to find what role a Genia could have in supporting in the professionals in their daily work.

From the interviews I gained an understanding for the different roles in the team, their collaboration and the routines regarding treatment planning for patients. In general the team members saw a positive potential with a mobile tool for children and adolescence to gain increased awareness about their own health.

“One important question for us that we ask is how the patients experience their respiratory health to be. The answer is often “I don't know”.

The clinician confirms that 80-90% of CF treatment builds on what the patient express about experienced health. For that reason it is seen positive with a tool that helps patients reflect upon their health, which can provide the clinicians with a more detailed picture. However, a concern is raised that a tool for health monitoring needs to be carefully designed not to become a burden for the patients, especially if targeted towards children. The perception is that if children get too focused on their disease it can have a negative impact on their wellbeing. This concern particularly relates to the ability to measure pulmonary function in the application. In the existing version of Genia one can store data of pulmonary function measured at home and get a graphical overview. This was seen as a crucial measurement in the initial development of Genia, being an objective measure of health state and a value of worth to the clinicians. However from the clinicians' perspective it is

important not to put too much focus on measuring pulmonary function at home. It is seen as measurement that could get too much focus, and if decreasing it could have a negative emotional impact on the patients. Despite these concerns, taking spirometry at home is looked upon positive if a patient suffers from an acute deterioration and needs careful monitoring. Burden and benefit needs to be balanced.

Co-design workshop

I WANTED TO engage the care team in development work, to enhance the opportunities of them to embrace the concept of Genia. I saw the need to identify what possibilities and challenges the professionals see with Genia, since the possibilities could provide insights for design opportunities, and challenges and fears could be discussed and considered, in order to better understand barriers of adoption. Hence a collaborative workshop with all members of the team was conducted.

Workshop description

THE TEAM MEMBERS were divided in to two groups with as many different professional roles in each group. Initially, the possibility of integrating mobile-based applications in to their IT system was presented, to provide an understanding for the new service system.

The workshop was built around two different patient personas, who the participants got to describe. A persona is a description of a typical user, often reflecting his or her needs, experiences and lifestyle. When personas have been created, these can be used in the process of design when visualizing fictive contexts of use (Cooper and Reimann, 2008). The purpose of making the workshop participants building the personas was to gain the healthcare professionals' perception of patient experiences, in daily life and in contact with the care team. The hypothesis was that this could reveal situations and tasks seen problematic from the healthcare perspective and how a mobile application for patients could be of use in collaboration with patients, from a professional perspective.

Each group got one persona. The groups were only provided with a picture of a person, with an age and name. From this point the participants got two assignments to solve collaboratively in the groups. As a start the participants were encouraged to provide a description of their persona in regards to personality, family situation and spare time activities. In addition they got to describe what their persona experienced as troublesome with CF in daily life.

After describing the persona the participants got to narrate a scenario of what happens in between visits and what contact the patient has with the team.

After these two group assignments the participants were now encouraged to think through three different questions to answer individually and then share in the group. The three questions were:

1. Regarding in between visits, what would be of advantage for you to know about the patient to help you in your work?

2. How would you like to receive this information? In the patient journal? In a team meeting? When meeting the patient?

3. What opportunities do you see, considering a tool like Genia, to help you in your daily work? Or can you think of something that would help the patient?

After this assignment was completed the two different groups presented their persona, the personas' experiences in between visits and finally how each participant had answered the individual questions. Reflections were then discussed collaboratively in the group.

Results of the workshop

FROM THE WORKSHOP two different patient scenarios were drawn out. Both patients in the scenarios had divorced parents, which shed light upon barriers in information sharing within the personal network, that can influence treatment adherence. Both patient scenarios revealed stories similar to my interviews with patients, how the respiratory exercise is perceived burdensome, and how it can be difficult to become independent in disease management.

The professional roles saw different opportunities with use of mobile application. The clinicians saw potential in getting a visual overview of information about a patients' health status and use of antibiotics. A visual representation could provide an overview, not available today, which could be a useful tool in addition to the patient's journal. Functionality of having a pre-visit form for the patients to fill in was seen as positive both for the care team and the patients, in order for both parties to be better prepared. However, the clinician described the importance of hearing the patient story as a complement to health data:

"The patient's story can really make the penny drop. I remember when we did a study where patients got to assess their health in a questionnaire; they felt very frustrated not being able to explain why they felt the way they did when ticking in the boxes. One patient answered



FIGURE 3.18
Workshop participants
describing the patient persona
and the patient scenario.

being really tired but when we discussed it later the explanation came “I was tired because I was out at the disco all night.”

Other professional roles such as the dietician and physiotherapist saw opportunities to communicate with patients between visits. A mobile application could be used both to check up on patients and provide motivation. The possibility to use an application as a channel for communication was especially seen positive in regards to out-county patients who visit the clinic only once a year.

”It would be good to be able to ask “How is it going?” and get a reply directly from the patient and perhaps give some positive pep talk.”

The nurse also saw the opportunity of providing patients with cus-

tomized information and education.

Summary

FROM THE TEAM members perspective three main opportunities are seen with a smartphone application connecting the private and the professional sphere:

- A possibility for the patient to reflect over health state, which could provide information to the clinicians and other team members for treatment planning. Some of this information could be shared by patients before the clinical visit in a pre-visit form, but also form a common ground for discussion when meeting with the patient.
- A mobile application could be a channel for communication between health professional and patient in between visits.
- Through a mobile application it could be possible to provide customized education and information to patients.
- A challenge or worry with the idea of a smartphone application for patients, is the risk of such tool becoming a burden for the patient, if focused primarily on self-monitoring.

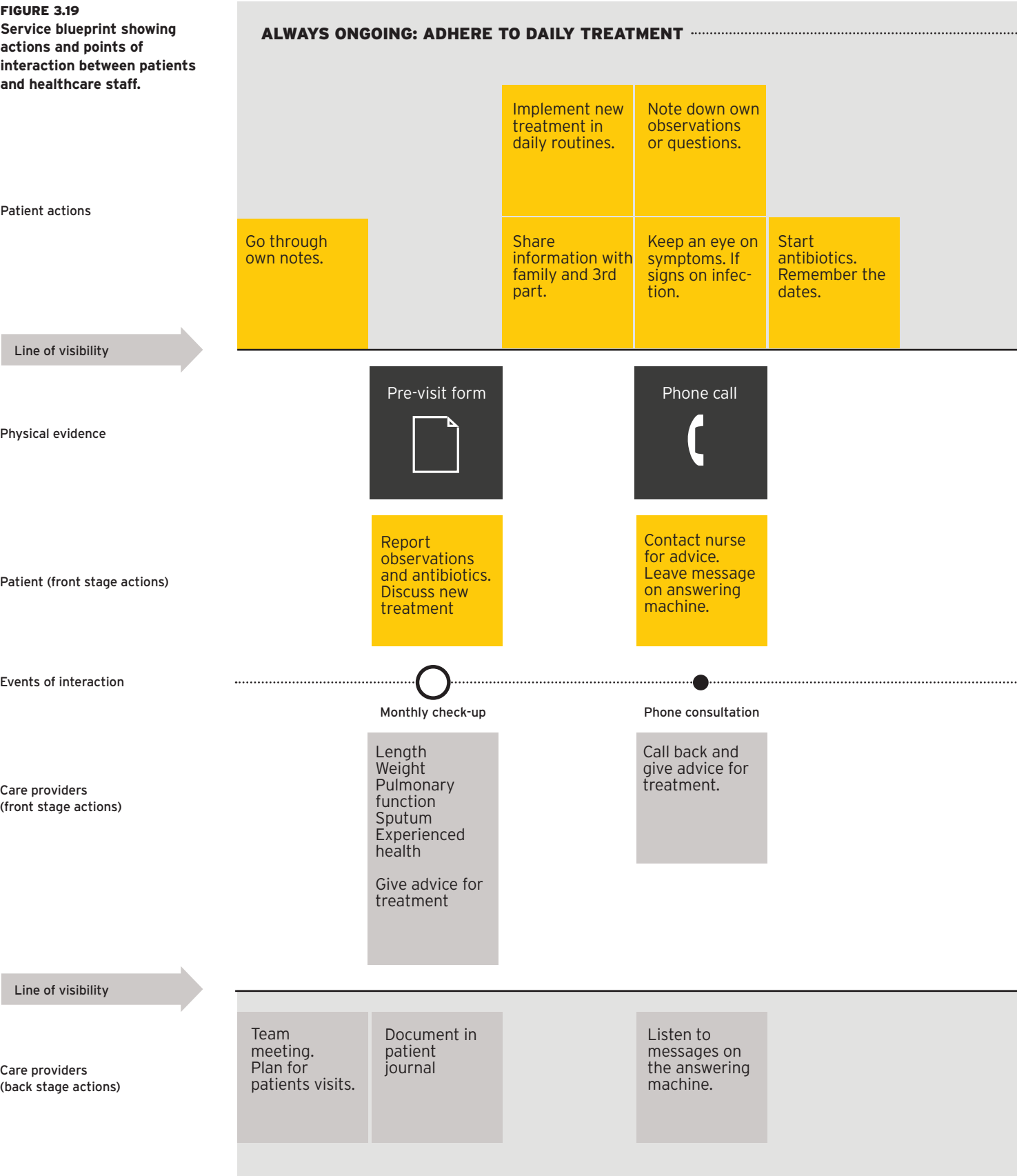
3.3. SUMMARY OF RESEARCH AND DISCUSSION OF FINDINGS

3.3.1. SERVICE BLUEPRINT & STORYBOARD

FROM MY RESEARCH I have found that daily life with CF can be complex but is also handled with different personal strategies in daily life. Different needs arise in different periods of life, for both patients and their close care givers. Even though families and individuals develop their own personal strategies for self-management, opportunities are recognized for a smart phone application to be a support in disease management in different ways.

The findings from my interviews with different stakeholders are collected in a service blueprint, on the next spread. The blueprint illustrates a patient journey for a CF-family, showing patient's and healthcare providers' actions and points of interaction between them. After the blueprint follows a storyboard that shows a similar scenario but describes the patient experience.

FIGURE 3.19
Service blueprint showing
actions and points of
interaction between patients
and healthcare staff.



DAILY ROUTINE EXAMPLE

Morning: Inhalation and respiratory exercise
Take medication. Physical exercise.

Extra meal and enzymes

Lunch: Medication and enzymes

Extra meal and enzymes

Night: Inhalation and respiratory exercise, physical exercise, medication

*In total
~2h*

Plan family logistics.

Go through and fill in information.

Implement new treatment in daily routines.

Phone call
Pre-visit forms



Share experienced health from the past year. Medications & antibiotics

Learn new treatment due to deterioration.

Plan for annual check-up

Scheduling
Send information.

Annual check-up

Full examination
All team members.

Physiotherapy week

Teach new treatment techniques.

Team meeting.
Plan for patient's annual check-up

Document in patient journal

Plan for physiotherapy week.

Document in patient journal

FIGURE 3.20

Storyboard describing typical issues that occur in between medical visits and in relation to monthly check-ups.

1.) Sofia, 13 years.



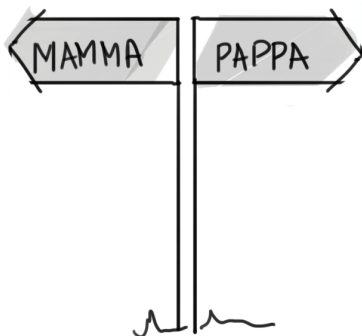
4.) Sometimes the training just feels so boring and heavy. No one understands.



7.) The doctor can give new medication, the physical therapist can give a new inhalation regime. Then it is important to remember and to be able to tell Mom and Dad.



2.) Mom and Dad are divorced. Sofia lives with each of them every second week.



3.) Sofia has CF and has to take meds, do inhalations and other exercises twice per day or more. Working out and keeping an eye on how she feels is important. Or she could get seriously ill.

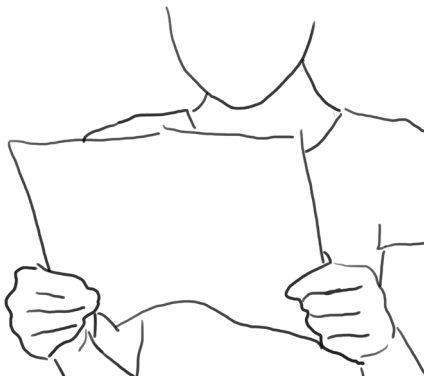


5.) Sofia goes to monthly check-ups at the CF center in the hospital every month. Sometimes she goes by herself, but mostly with either Mom or Dad.



At the montly check-up, the doctor asks hos Sofia feels. How are you? It can be good for now. Just fine. But maybe it was worse last week. It is difficult to give a good picture in a short time.

6.) If one goes alone to the CF center, there is like a whole book of things that Mom has written down that she wants to bring up.



8.) One week when Sofia is at Dad's she gets ill. Dad calls the hospital. They say that Sofia shall start with antibiotics.

9.) Next time when they are at the CF Center, Mom doesn't know when Sofia was ill and what antibiotics she got. Sofia doesn't quite remember.





FIGURE 3.21
Findings from research that forms three design drivers.

3.3.2. DESIGN DRIVERS

The findings are summarized into three sections that forms the design drivers. Even though possibilities are seen for Genia to be used by several age groups, the foremost age group to consider in design is seen to be children between 10 and 15 years. This is the age span when starting to take more personal responsibility in self-management of disease, simultaneously this is the age where children often start to use own smartphones. Hence, the design drivers focus primarily on a target group of children between 10 and 15 years and their families.

Support collaboration between the private and the professional sphere

MY RESEARCH CONFIRMS the need of a support in understanding CF on an individual level, and in making the monthly visits at the clinic more informed, which is the core idea of Genia. Being more informed is seen to improve care. This need is clearly reasserted by the clinicians, as

80-90% of CF treatment builds on what the patient and family inform them of experienced health. Simultaneously from patients I discern difficulties in sharing experiences and a wish to get better understood by healthcare professionals. Hence the application should support both collection of data, and sharing of experiences related to the personal health. There is an expressed difficulty to see patterns appearing over time and to connect experienced symptoms with action (advised treatment) and result (experienced health). Opportunities are seen to increase learning and understanding by enabling for analysis and reflection.

Even though a clear value is seen in supporting collaboration, to better understand and treat CF on an individual level, it appears to be a quite complex situation. Children can find it burdensome to reflect on their own health. Concerns are raised from care professionals that self monitoring of health can have a negative emotional impact if pushed on children. This concern is not groundless, other studies show evidence of such impact (Peel et al., 2003). Children and young adolescents with CF could though benefit from having a support in gradually taking more responsibility for self-management of disease, and reflect somewhat more over their health state.

Even if focus lies on making the monthly visits more informed, opportunities are seen to practically facilitate communication between patient and care provider in between visits. An effortless channel for communication is seen positive both from the patients and providers point of view.

Support management of care in every day life

APART FROM BEING more informed about health state, my research also shows a need for structure of information and tasks related to CF in daily life. The personas created by the CF-team also showed on barriers in information sharing in families with divorced parents. Hence there is an opportunity for the application to support care management by facilitating collaboration in the private, and by providing a structure for information and documentation.

Motivation to treatment and relatedness with others

FROM THE CHILDREN'S' point of view, and also from older patients reflecting on their childhood, it becomes clear that the daily treatment, and especially the respiratory treatment can be experienced as boring and bothersome, which causes nagging from parents. Older patients reviled stories of skipping treatment, with the argument that no one of their

friends had to do it. Opportunities are seen to design for motivation to the daily exercise, a common purpose in applications for fitness and training. When imagining a smartphone application for CF patients, most children that I interviewed saw it having a social function. Since CF patients are advised not to meet in person, potential is also seen to create a sense of belonging and relatedness with others, a factor supporting intrinsic motivation according to the Self Determination Theory (Ryan and Deci, 2000).

3.3.3. DISCUSSION

TO CONCLUDE, ONE primary driver of Genia is to facilitate for collaborative and informed meetings between patients and care providers, and for individual learning about disease. The existing application had this aim, however it needs to be re-designed to better fit individual needs, and to facilitate sharing, reflection and learning. Consideration needs to be taken to the aspects of self-monitoring, to try to avoid a negative emotional influence. In addition, two other drivers are set up based on the research findings, to ease management of care in daily life and to motivate adherence to treatment.

To reach the full potential of Genia I find that the application should be targeted not only towards children, but to the whole family, where the child's own usage can increase over time. Strategies for self-management grow with time, which support to follow the guidelines of enskilment, to design for tools that allow for growth of skill (Kilbourn and Buur, 2007). The expressed wish to better understand the individual CF similarly relates to what is proposed by Ballegaard and colleagues, to design for learning related to daily life (Ballegaard et al., 2008).

Opportunities are seen for Genia to support the psychological needs of competence and relatedness, through understanding and learning more about the individual CF and through interaction with others, which when supported have shown positive outcomes of health, adherence and engagement to treatment (Ryan et al., 2008).

Delimitation

MY RESEARCH SHOWS that there is a large network of services and stakeholders involved when managing daily life with CF. Daily tasks such as going to the pharmacy, or getting extra nutritional food in school are two examples of other services and stakeholders involved. Regarding connection with other systems, I chose to frame my work to the interaction with healthcare providers, considering the timeframe

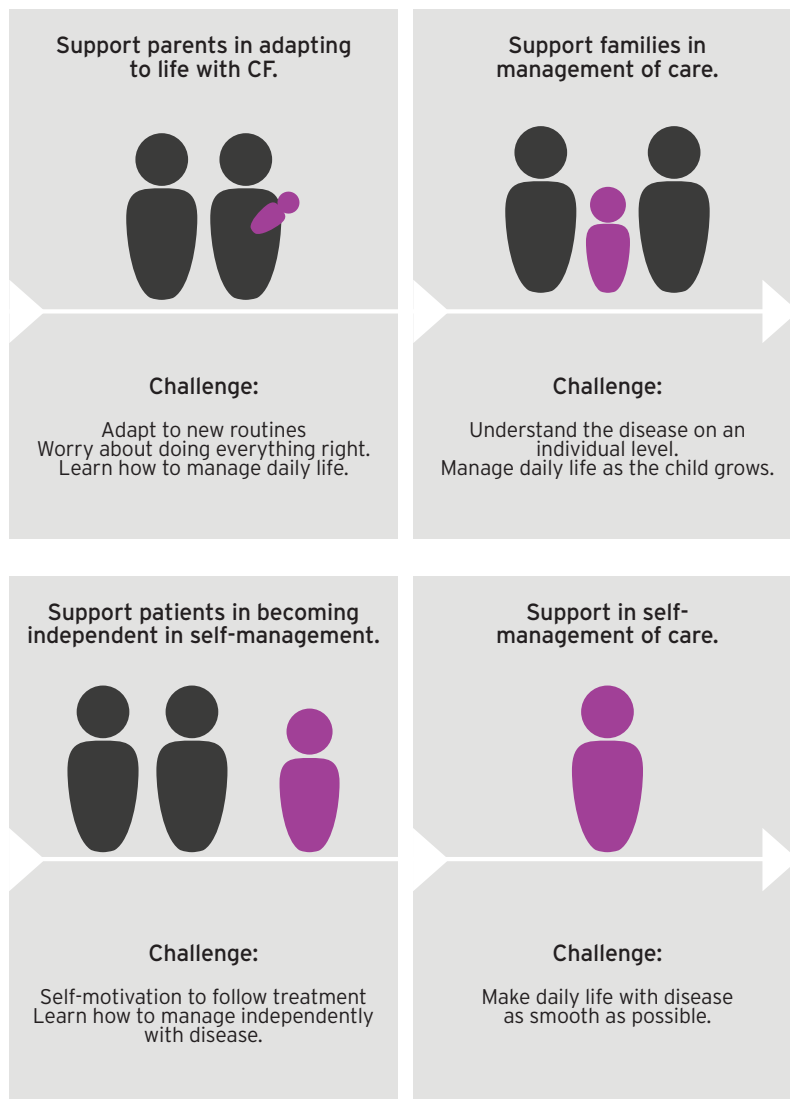
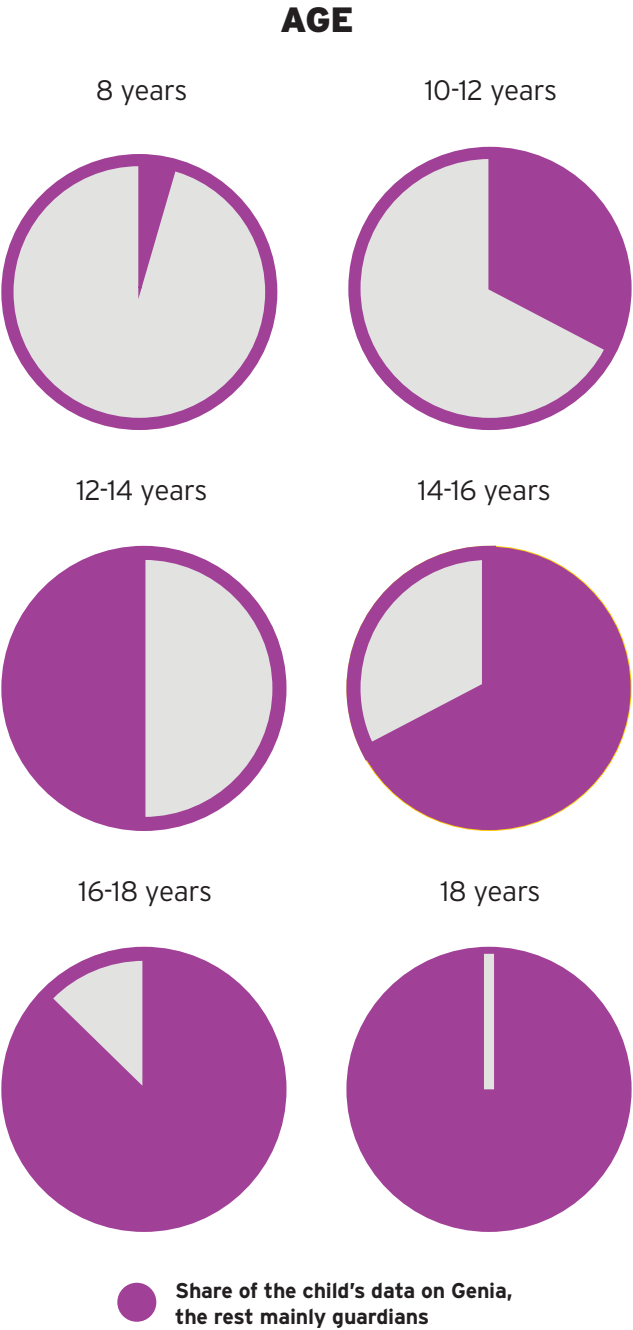


FIGURE 3.22
Opportunities for Genia
to support in different
periods of life, showing
the change in needs and
target user over time.

of this thesis. Thus, as for future development, there is a recognized possibility for Genia support in managing daily life with CF by interacting with other parts of the service network involved in the daily management of CF.

FIGURE 3.23
Genia, a platform for the family that is shared by parent and child. The child's use and ownership increases with time.



3.4. CONCEPT DEVELOPMENT AND DESCRIPTION

3.4.1. AN APPLICATION THAT GROWS WITH THE USER

AS ACKNOWLEDGED PREVIOUSLY, needs change overtime as well as strategies for self-management, hence an application could provide different support in different periods of live. Looking at Genia from a bigger perspective, with several groups of users, and acknowledging the need for customization and personalization of such tool, a clear strategy to build the application around widgets became evident. Widgets could be described as building blocks with different functionality that can be used within a platform. Hence it could be possible to customize the application with widgets of own interest and needs, enabling the application to grow with its user, and for growth of enskilment. The primary target group was set to be children and young adolescents on their way to independence in disease management, hence the concept is designed primarily for this target group, including their parents.

Similar to the previous version of Genia this concept also builds upon having several users connected to one account to facilitate collaboration and information sharing within the personal sphere.

Four different widgets were designed with starting point from the design drivers described previously. The following sections will describe each widget and the reasoning behind design decisions. In my presentation I have chosen to use the iPhone as an icon of a smartphone.

3.4.2. SUPPORT COLLABORATION BETWEEN THE PRIVATE AND THE PROFESSIONAL SPHERE

FROM MY RESEARCH I saw the need for a design, enabling not only for collection of health data, but for reflection, which could function as a support in collaboration with care professionals around treatment planning. The design should also allow for sharing of experiences related to the personal health. My research showed a need for a solution that enables a personalized data collection, since symptoms within CF varies greatly, as well as experienced health. In in periods of deterioration, more careful and detailed observations might be needed, and in times when experiencing periods of good health, observations might

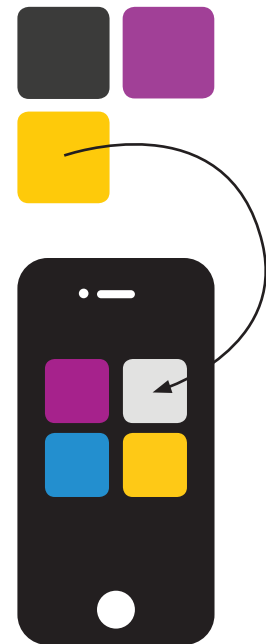


FIGURE 3.24
To allow for enskilment that happens over time the concept builds on widgets adaptable for individual needs.

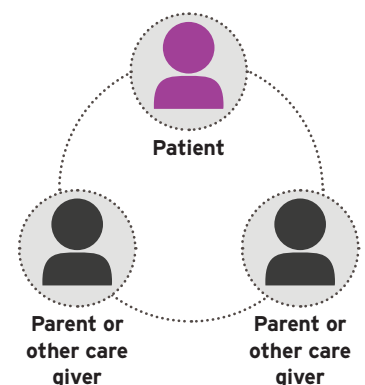


FIGURE 3.25
Individuals in the private network are connected to one patient account.

not be seen as important. Hence, the system should provide for variations between such tight and loose structures. A large focus in design has been to create a concept which fulfills these needs but still fits into a defined frame that makes analysis and reflection possible.

Observations of Daily living

IF LOOKING AT trends and future scenarios in healthcare there is a growing interest for sensors measuring different factors in our bodies. In the near future it will probably be possible to register cough frequency and similar CF related symptoms accurately. One path to go down would be to design for a future scenario where self monitoring is enabled by such sensors. Such technology could passively monitor symptoms and could for example alert the user when showing symptoms out of normal. However, even though these opportunities were considered, I found it more interesting to design a concept implementable today, building on technology already available through the smartphone. I also deliberately took a step away from a concept building on rigorous self-tracking of symptoms and data, avoiding the possible negative emotional impact this can cause. Instead I wanted to put weight on personal observations of daily living, to enable personal and collective learning related to daily life, a guideline proposed by Ballegaard and colleagues (Ballegaard et al., 2008). In addition, two major strengths of observations of daily living are acknowledged in research. ODLs can increase awareness of one's personal health, which enables making informed decisions, but it can also provide care providers with an increased understanding for the patient context (Backonja et al., 2012). The necessity to design for flexible and highly personal ODLs also came clear when investigating the existing Genia application. The symptom scales were not used, instead the free notes were used more, since the symptom scales were seen as not being descriptive enough in relation to the specific events or experiences.

Experience vs memory

A SITUATION CAN be perceived very differently in the actual moment of experience compared to how we later recall the memory of the experience (Kahneman, 2010). Hence one of the strengths of using a mobile device for daily observations is the possibility to document experiences in context, in the moment of occurrence. To facilitate a richer and more detailed capturing of experience and symptoms, than by only using words, I wanted to provide the ability to use various media

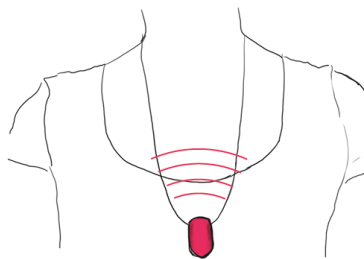


FIGURE 3.26
Idea of sensors measuring
cough frequency.

such as images and sound. Images can recall memories or show details difficult to describe with text. One example for how images can influence clinical care is in documentation of sputum. Color, thickness and structure of the sputum, informs clinicians of the patient's pulmonary health. This can be difficult to describe with words, instead a picture provide clinicians with more nuanced information.

Collaboration in the private sphere

ODLS SHOULD BE possible to register collectively by several people in a family, connected to one account. This is for several reasons. It can be difficult to view one's own health state objectively. One girl said that she gets so used to her cough that she doesn't even think about it, until her mom points it out for her. My research also revealed that children might perceive it burdensome to reflect on their own health often, hence the parents and child could make ODLs collaboratively. To have a shared account also facilitates communication and information sharing between family members that do not live together.

See patterns and changes in health state over time

IN INTERVIEWS WITH families and the healthcare team, it became clear that an overview of health state over time was desired. A visual overview of health data could both provide a sense of control, but also allow for personal learning as well as sharing of experiences with healthcare providers. In CF, effects of treatment are often deferred, and symptoms can vary depending on the season of the year. Hence I wanted the design to enable a visual overview of data, covering longer periods of time, which should enable reflection on yearly basis.

My research showed that in connection to the ODLs, data of antibiotics would be beneficial for both the patients and care providers to store and overview. Patients could feel more in control in getting such overview, to avoid the risk of taking similar kinds of antibiotics too often and become resistant. An overview of antibiotics in relation to health state could also be a base for learning about the individual CF and provide an understanding for how one respond to different kinds of antibiotics. From clinicians' perspective, the overview of antibiotics could be a complement to the data in the patient's journal. Today clinicians document the patient's use of antibiotics with paper and pen, in order to get an overview, since there is no IT solution for this purpose.

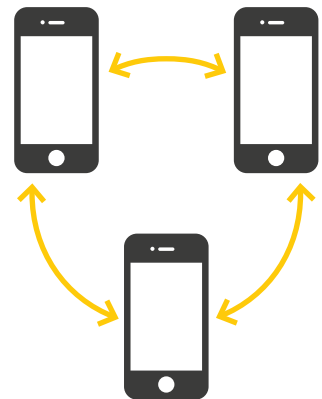


FIGURE 3.27
ODLs can be made collectively by all individuals connected to the patient account.

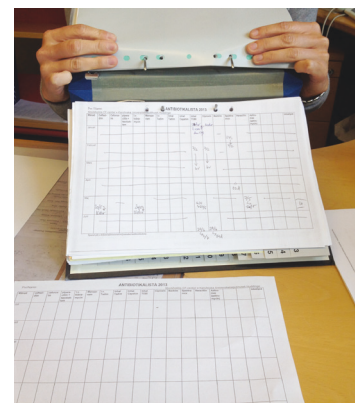


FIGURE 3.28
Clinician's notes of antibiotics.

Final design of widget for ODLs

THE FINAL CONCEPT for ODL:s is a widget called 'What's up?' ('Hur är läget?'), described below.

FIGURE 3.29

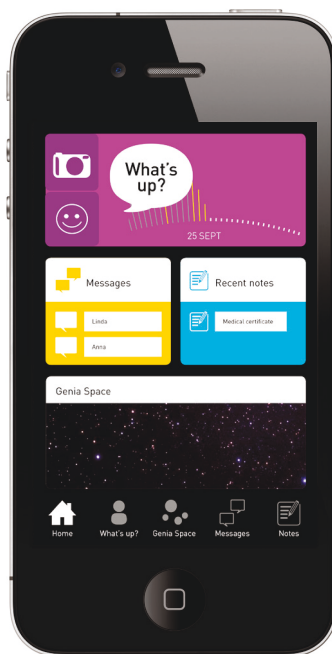
The concept for observations of daily living, designed to facilitate collection and sharing of - and learning from - data related to experienced health.

1.) Front page showing the different widgets. The function for ODL's is called What's up.

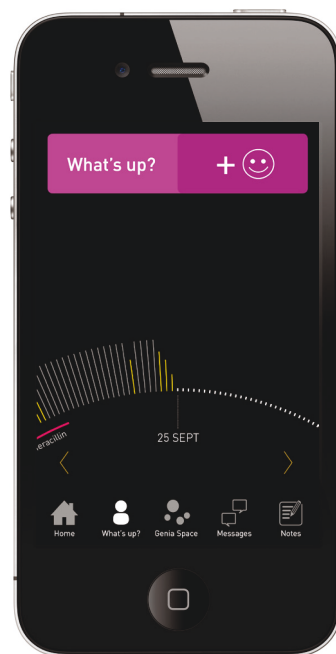
2.) Data is shown in a scrollable timeline. Click to add an ODL to the active date.

3.) Assess wellbeing by choosing facial expression on the smiley. Add an optional comment. Possibility to add picture, antibiotics or spirometry.

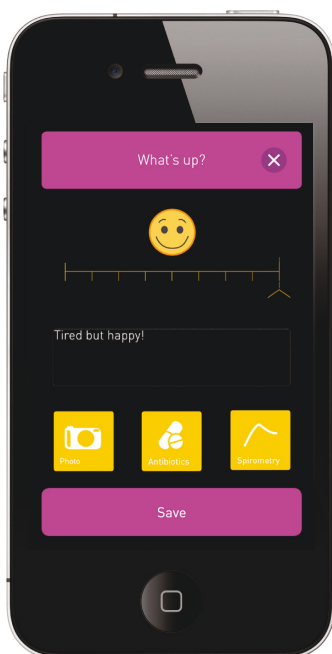
4.) The post is shown in the timeline, which can contain comments from several members in the family. The length of the yellow bar reflects level of wellbeing. The grey bars reflect days when no observations are made.



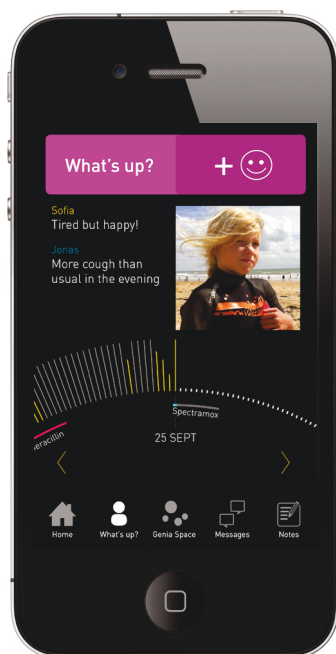
1.)



2.)



3.)



4.)

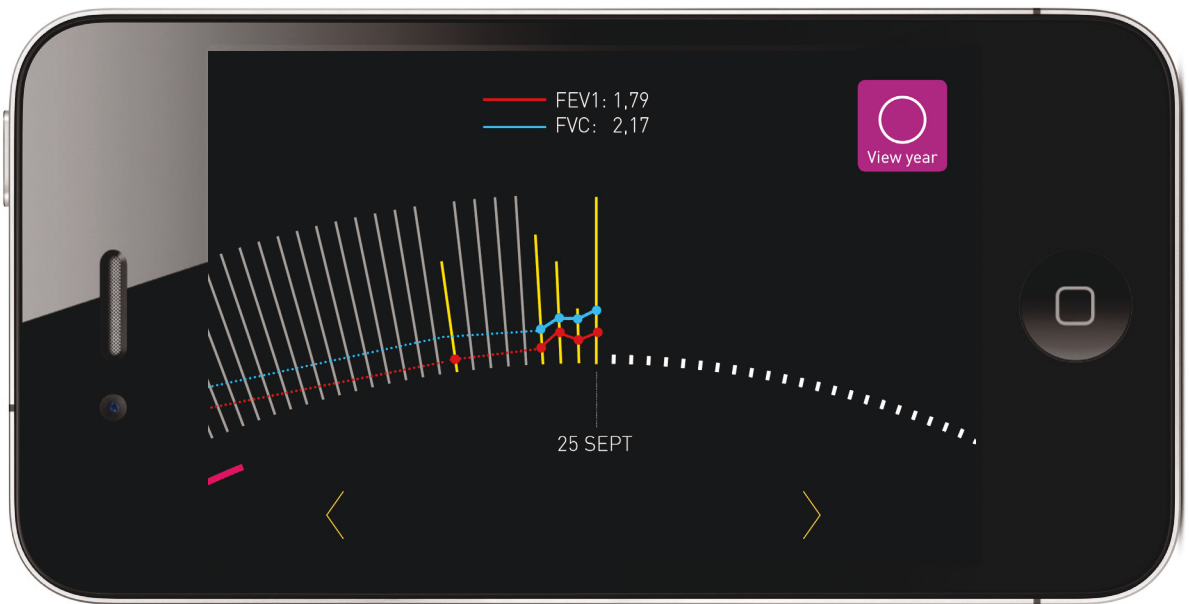
FIGURE 3.30

Level of wellbeing can be overviewed in connection to objective data such as spirometry and antibiotics.

1.) If rotating the phone, graphs of spirometry are shown in the timeline.

2.) It is also possible to view the timeline showing the whole year. In this way it is easy to get an overview of disease periods and when taken antibiotics.

1.)



2.)



THE DESIGN ALLOWS for documentation of ODL's relevant to the personal health, as well as courses of antibiotics and biometric data such as spirometry. However the main focus is not on biometric data, but on the individual wellbeing. The design is meant to allow for analysis and personal learning as well as sharing experiences in the clinical encounter. The data is visualized in a timeline which provides an overview of experienced wellbeing over time, connected to objective data (such as spirometry, and antibiotics). With the graphical display of data in this way, it is possible to get an overview of disease periods, as well as detailed information of health state and symptoms, when flickering through the timeline. In this structure and form the design support the guidelines of a) Design for continuity and b) Design for understandability and learning related to daily life (Ballegaard et al., 2008).

Other studies on patient ODLs and the implementation of such into clinical workflows showed a worry from clinicians to be overflowed with patient generated data, and from the patients' side a concern around privacy and confidentiality (Backonja et al., 2012). This concept aims to avoid these issues and instead of sharing all data through an IT system, it provides the possibility for patients to bring their own data with them to the clinical visit, to be used as a common point of thought for both clinician and oneself. In this way the patient can choose what to share and not.

**FIGURE 3.31**

Bringing data and own observations to the clinical visit can function as a common point of thought, and a support in collaborative meetings. Genia can be used across a variety of platforms to fit for purpose of usage. In this case a tablet would be the suitable format.

3.4.3. A CHANNEL FOR COMMUNICATION WITH THE CARE TEAM

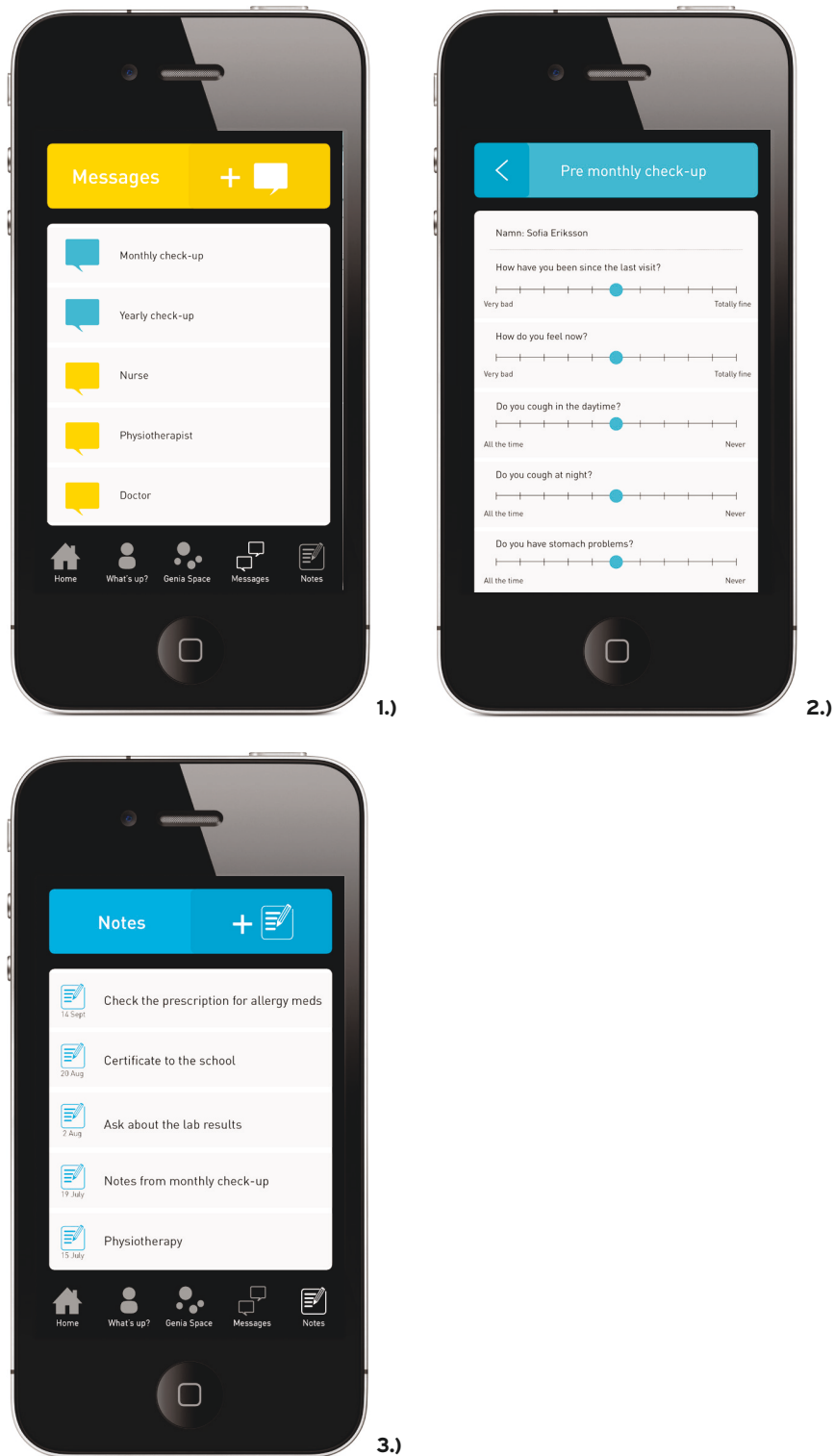
ANOTHER ISSUE THAT came up during my research, which also relates to collaboration between the professional and the private sphere, is the sometimes difficult matter of reaching the care team. This was foremost a concern amongst out-county patients. With the IT structure that is currently under development in Sweden, it could in the future be possible to create a channel for communication between patient and care provider through an instant message function in the application. Often personal contact with the nurse is needed and very appreciated, but for smaller matters, both care providers and patients could be helped by a channel for short messages. A widget was designed for this purpose, called Messages (Kontakt). Today the team nurse answers all the calls and directs them to the right person, however, with the message functionality, communication could be facilitated directly with the person of concern.

Pre-visit forms

THE MESSAGES WIDGET also includes pre-visit forms that can be sent to the clinic before the monthly or annual check-up. Pre-visit forms are used to make both parties better prepared for the meeting at the clinic. The pre-visit forms in the application builds on the ones that the clinic currently use, except the questions are slightly re-phrased in a less clinical language, and specifically directed to the patient in focus, that is the child. The information sent through the forms can be directly integrated with the care providers' patient journals, and also linked to the quality registry for CF. The IT structure behind the forms connects with the national eHealth-service system and requires use of standardized templates.

3.4.4. STRUCTURE AND SENSE OF CONTROL

MY RESEARCH SHOWED a need for a structured place to keep CF related notes and information, to create a sense of control. Hence a widget for keeping notes not directly connected to ODL's was seen as a priority function. Notes can be attached to dates in the timeline, which facilitates keeping a structure of matters relating to a specific event, such as a clinical visit. Even if family members share one account, it is in the notes function possible to keep private notes, only for one self to see. Privacy might be requested in some cases, when growing up to become independent from parents.

**FIGURE 3.32**

**Design of the widgets
Messages and Notes.**

**1.) Message widget where
instant messages can be
sent to care providers.**

**2.) Pre-visit form available
in the Message widget. Can
be sent to care providers
before a clinical visit.**

**3.) An example for how Notes
can be used. The widget can be
a place for documenting what is
agreed upon at the clinical visit
and things to remember.**

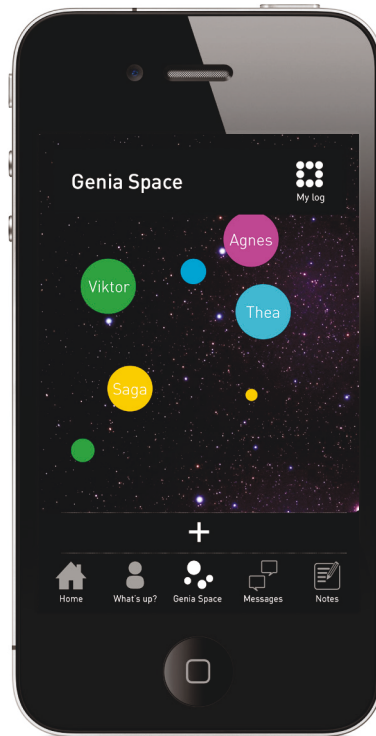
FIGURE 3.33
Description of Genia Space

1.) Once exercise is done, put a bubble out into space, which shows other bubbles coming out in space in real time (other children who have done their daily exercise).

2.) Attach a comment to the bubble...

3.) ... and read others'.

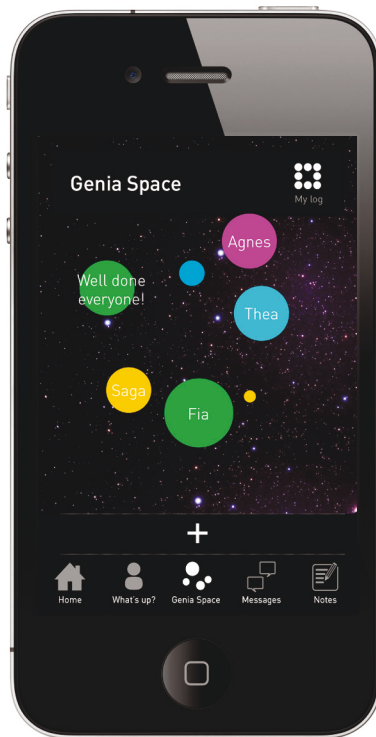
4.) Get an overview of how the exercise is going, put up own short term goals.



1.)



2.)



3.)



4.)

3.4.5. MOTIVATION TO DAILY TREATMENT

THE FOURTH WIDGET, Genia Space, foremost aims to support motivation to daily treatment, being one design driver. Literature on motivational theories show the importance of activating intrinsic motivation for behavioral change to be performed and maintained (Ryan et al., 2008). Hence the aim has been to design for usage that could activate intrinsic motivation. Most of the children that took part in my research saw a mobile application as naturally to be used for social interaction. The fourth widget, Genia Space, is thought to function both as a training diary, and as a platform for interaction between CF-patients. CF patients often do their respiratory exercise in the morning and one time in the evening. The idea with Genia Space is to give the children a possibility to see that they are not alone in doing their daily treatment, which could provide a sense of relatedness with others. According to the Self-determination Theory the feeling of relatedness is one factor supporting intrinsic motivation (Ryan et al., 2008). Simultaneously the training log enables individuals to put up short term goals to reach, which could enhance the feeling of control, another factor stated to promote intrinsic motivation (Malone and Lepper, 1987).

The concept of Genia Space as designed here should only be seen as a starting point for a platform that can be further developed. More detailed design work could show opportunities for activating and maintaining motivation, perhaps through more extensive use of gamification. However, I believe the application of game elements needs to be thoughtful, aiming to trigger the inner motivation amongst individuals, as advised in theories for motivation, since the concept would not be very useful if only being a fun gimmick, used over two weeks time.

3.5. OVERVIEW OF DESIGN CONCEPT

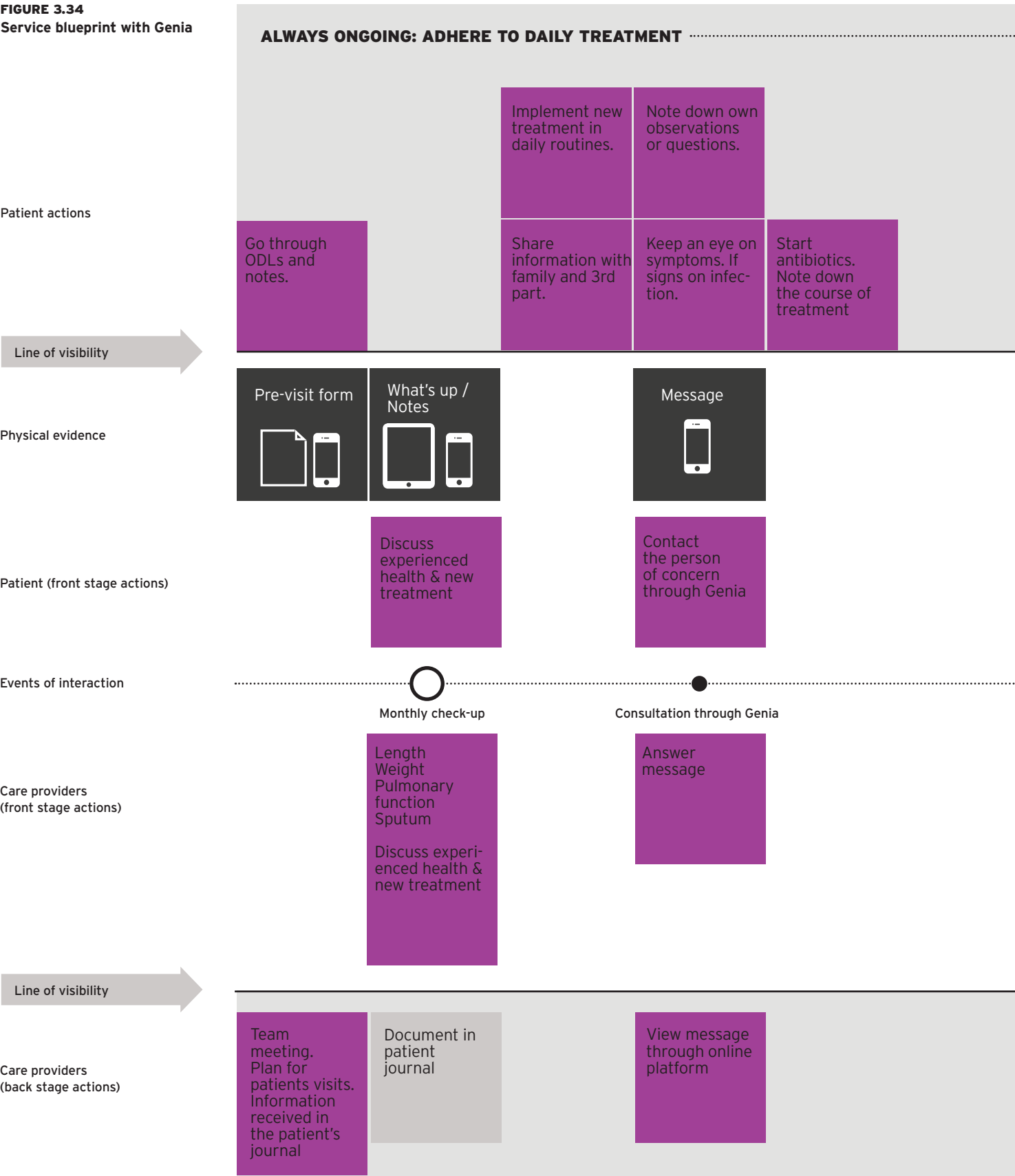
Service blueprint with Genia

THE SERVICE BLUEPRINT that follows shows the service process with Genia, the fields marked with purple, highlight areas which the Genia concept are seen to influence.

User scenario

THE CONCEPT IS also described in a user scenario, focusing on how Genia could influence the patient experience.

FIGURE 3.34
Service blueprint with Genia



DAILY ROUTINE EXAMPLE

Morning: Inhalation and respiratory exercise
Take medication. Physical exercise.

Extra meal and enzymes

Lunch: Medication and enzymes

Extra meal and enzymes

Night: Inhalation and respiratory exercise, physical exercise, medication

*In total
~2h*

Plan family logistics.

Go through and fill in information.

Implement new treatment in daily routines.

Phone call
Pre-visit forms



What's up /
Notes



Share experienced health from the past year. Medications & antibiotics

Learn new treatment due to deterioration.

Plan for annual check-up

Scheduling
Send information.

Annual check-up

Full examination
All team members.

Physiotherapy week

Teach new treatment techniques.

Team meeting.
Plan for patient's annual check-up

Document in patient journal

Plan for physiotherapy week.

Document in patient journal

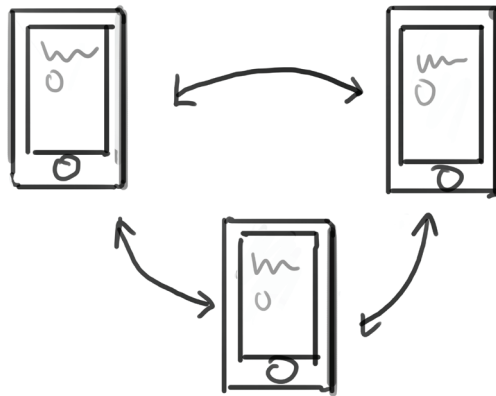
FIGURE 3.35

The concept described in a user scenario showing how Genia can support in daily life and facilitate collaboration in care management.

1.) During the month, Sofia can make short notes about how she feels, and if there is anything special that has happened, like taking antibiotics.



2.) Sofia would rather not have to think so much about having CF. So it is good that Mom and Dad also can make notes about the treatment and symptoms in everyday life. The data is shared so everyone knows.



3.) Sometimes it is difficult to reach the CF-team at the hospital. If there is something that doesn't need to be discussed over the phone, one can just send a text and they reply as soon as possible.



4.) With Genia one can send info to the hospital in advance so that the team can plan better for the visit.



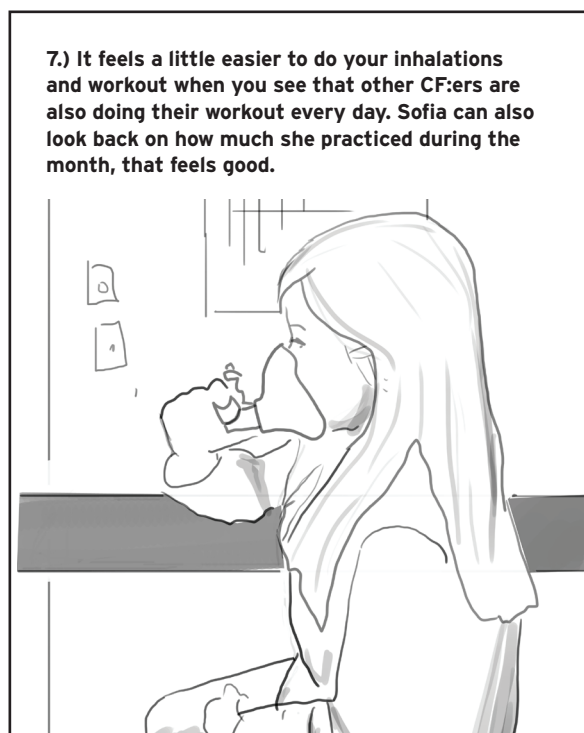
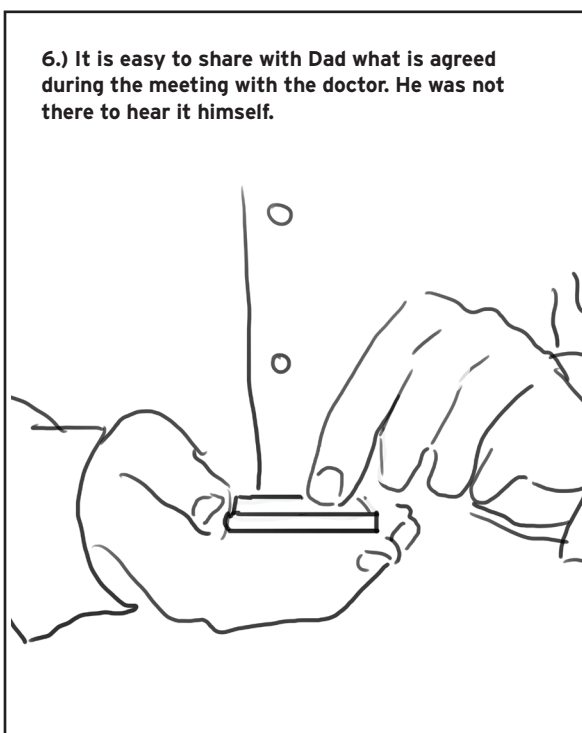


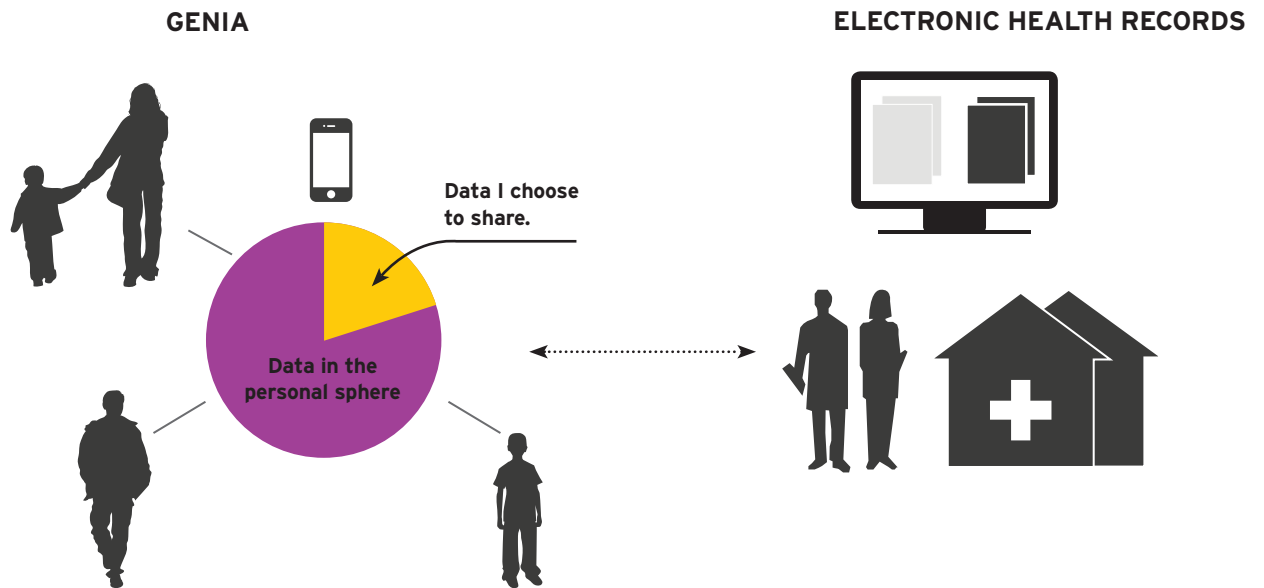


FIGURE 3.36
Overview of the four different widgets and the design drivers.

3.5.1. CONNECTION TO THE NATIONAL E-HEALTH SERVICE SYSTEM

SINCE THE SWEDISH service system for mobile health is not yet established at the time of writing it is not possible to give a defined description of the system and Genia's locus in this. However, even though Genia's connection to the national e-health service platform is not yet established, the flow of information between care provider and user will be enabled and structured as described in Figure 3.37 (the authors understanding from published information) (Vårdkontakter, 2013, Lind, 2013). Only information that the patient or the patient's legal guardians authorize to share will be transferred to the care providers' IT system. This information is required to follow certain structures, in order to integrate with the care providers EHR. In Genia, structures for such sharing is enabled in the pre-visit forms. Electronic ID will be demanded from the private user to authorize transfer of information. The information sent through this system will also be possible to connect to the quality registry for CF patients. Such data could be used for research purposes and lead to collective learning about CF for improved outcomes of care.

RIGHT PAGE:
FIGURE 3.37
Map of information flow between Genia and the national e-health service system.



THE PERSONAL SPHERE

Patient's own data. Use of 3rd party services such as Genia.



Export area. Data that fulfill the demands of structure to be documented in EHR. Requires use of defined templates. In Genia, the pre-visit forms.

API Gateway, a security service that fulfills demands of encryption, authentication and validation. Requires electronic ID from the private user.



THE PROFESSIONAL SPHERE

Information to be shared with the patient.



Care providers' patient journal



FIGURE 3.38
Inspiration from health
applications and devices on
the consumer market.

TOP:
Nike Fuelband
http://www.nike.com/us/en_us/c/nikeplus-fuelband

BELOW:
Jawbone UP
<https://jawbone.com/up>

3.5.2. USER EXPERIENCE AND GRAPHIC DESIGN

THE LOOK AND feel of the app foremost aim to appeal the primary target group of children between 10 and 15 years. Nevertheless the design of the different widgets aims to facilitate and promote collaborative use from a whole family, or others in the personal network. The exception is Genia space, which is seen as the child's personal space. As noted in the literature study there is a gap in user experience between tools and applications designed for the care setting and applications designed for the consumer market. In look and feel I wanted to step away from the clinical feeling related to products designed for healthcare. Devices designed for the clinical environment, focusing solely on pragmatic attributes, does often not respond well to individuals' personal identity (Bispo and Branco, 2008). Even if the reason behind using Genia is because of having CF, I wish not make the user feel their personal identity is reduced to the one of 'a patient'. I wanted the design to appeal to children, and be something they can relate to, supporting them in their role of becoming independent, feel in control, and be actively involved in their health. Fitness applications for the consumer market are often playful and colorful. I wanted Genia to have more of a such positive image, compared to what is seen in traditional healthcare devices. Inspiration is also taken from technical sports products, devices with a high tech feeling, which somehow gives the user a feeling of achievement in mastering a challenging task.

3.6. EVALUATION

3.6.1. EXPERIENCE PROTOTYPING

AN INTERACTIVE PROTOTYPE of the concept was built up to test and evaluate it with future users. The prototype aimed to provide an experience close to a functioning application in terms of user experience. This way of experience prototyping, giving the user possibility to directly engage with and experience a product or service, gives richer subjective feedback when evaluating design ideas (Buchenau and Suri, 2000). Even though the prototype was not fully functioning, it gave the possibility to gain insights in how users experienced the concept.

Evaluating user experience

IN EVALUATION I took inspiration from the AXE method (Anticipated eXperience evaluation), a qualitative method for evaluating user experience which considers both pragmatic and hedonic qualities, i.e. both usability and personal identification or stimulation of a concept (Gegner and Runonen, 2012). The method uses visual stimuli, in form of opposing image pairs, as a starting point for reflection. The reflections are later analyzed and categorized in to positive or negative experiences, and if being either related to hedonic or pragmatic qualities. The visual stimuli was seen especially suitable for evaluation with children, as a way to start a discussion around their experience, additionally the method takes into account the hedonic experiences of a concept, which had been one focal point in design. However, the method was not used to make a detailed analyze. Due to time limitations I could not carry out the deep interviews required for such analyze, instead the participants' reflections around the image pairs functioned as a starting point for discussion which gave insight in the different aspects of the user experience.

Some of the image pairs (provided by the method) were modified, to better fit evaluation with children. Two evaluation sessions was carried out, with two families. The author described the concept through the user scenario and the interactive prototype, which the family members got to try out themselves. Then both parent and child got to indicate in a form how they related the concept to the different image pairs. After filling out the form the participants were interviewed about their reflections.

"I like that it helps out, then I can relax more"

"It's very useful, I love the wheel!"

"It does not feel cluttered I feel it is very structured and clear, and that makes me happy."

"It's stylish, it appeals to me"

Result

OVERALL THE USERS' reflections of the concept were very positive, both concerning pragmatic qualities and hedonic attributes. The participants thought that the timeline, reflected on as "the wheel" could be a useful tool for both personal learning and when discussing with the healthcare team. Other comments such as "I like that it helps out, then I can relax more" gives support for that the application, at least to some extent, reaches the goal of design to ease management of care in daily life.

However an anticipated negative experience was raised by a parent, that of the application becoming a stress to fill in. "I'm thinking that it might become a stress to fill it in, it might cause a bit of guilt, one must find the routines for it"

Another concern raised was the message function to contact the care team. It was seen as very useful function but parents acknowledged the importance of the system to also be used by the care professionals, and that one can know that the message is read.

I understand that the Genia space widget, focusing foremost on motivation to daily treatment, directed specifically to the children needs further exploration and iteration. The two children participating in the evaluation was eight and twelve years old. The eight year old could not really relate to the idea of an interactive virtual space. The twelve year old girl suggested the interactivity to be further exten-



FIGURE 3.39
Visual evaluation material
inspired by the AXE method.

ded to be more useful. She saw a positive aspect in giving each-other inspiration and tips for exercises in Genia Space. She also saw a positive potential in putting up more detailed goals of exercises for a week. However these more detailed goals she saw as something to be kept private, avoiding a feeling of competition with others, that otherwise might arise.

Since I could not provide the users with a functioning prototype to use over some period of time, I asked them to reflect in daily life on how they saw they would use the application, to see if this reflection would give further insights. The participants were contacted again after one week's time.

In the follow-up interviews, the users suggested some additional functionality they thought could be helpful, such as the possibility to keep a food diary within the app, which some patients have to keep and share with the healthcare providers.

3.6.2. DISCUSSION EVALUATION

A CONCEPT LIKE this can be difficult to evaluate before actual usage in real life. The participants could only imagine how they would use the application and further evaluation would be useful to perform after some period of using a functional app. Since usage is affected by context and social actions, another approach could have been to focus on prototyping social interaction, suggested by Kurvinen and colleagues (Kurvinen et al., 2008). The approach is focused around exploring the social activities that evolves through usage of for example mobile multimedia, and to understand how people interact with others while using a prototype (ibid). For example it would have been interesting to explore how usage of the application would influence the clinical encounter. Though, considering the timeframe and resources for this thesis I did not have the possibility to prototype the concept in that manner. Hence, it is difficult to say how the application will affect collaboration between care providers and patients. One aim in design was to facilitate for the children in sharing experiences with their care providers. The parents comments were very positive, however due to time limitations in my evaluation I didn't have the possibility to gain understanding for how the children perceived the application could support this matter. The notion of 'Design for design after design' as this concept to some extent is trying to embrace, by not providing fully designed solutions, but platforms for collaboration, is seen to be difficult to evaluate when prototyped in this manner.

3.6.3. ROADMAP FOR THE FUTURE

THE FOUR WIDGETS designed can be seen as core widgets of the Genia concept, targeted towards families and children between 10 and 15 years. However, potential is seen to expand the range of widgets to meet the needs of a larger user group.

Currently, Genia exists only as a smartphone application, but benefits are seen of expansion, becoming a platform for disease management which could function as a personal health record for CF-patients.

ROAD MAP GENIA

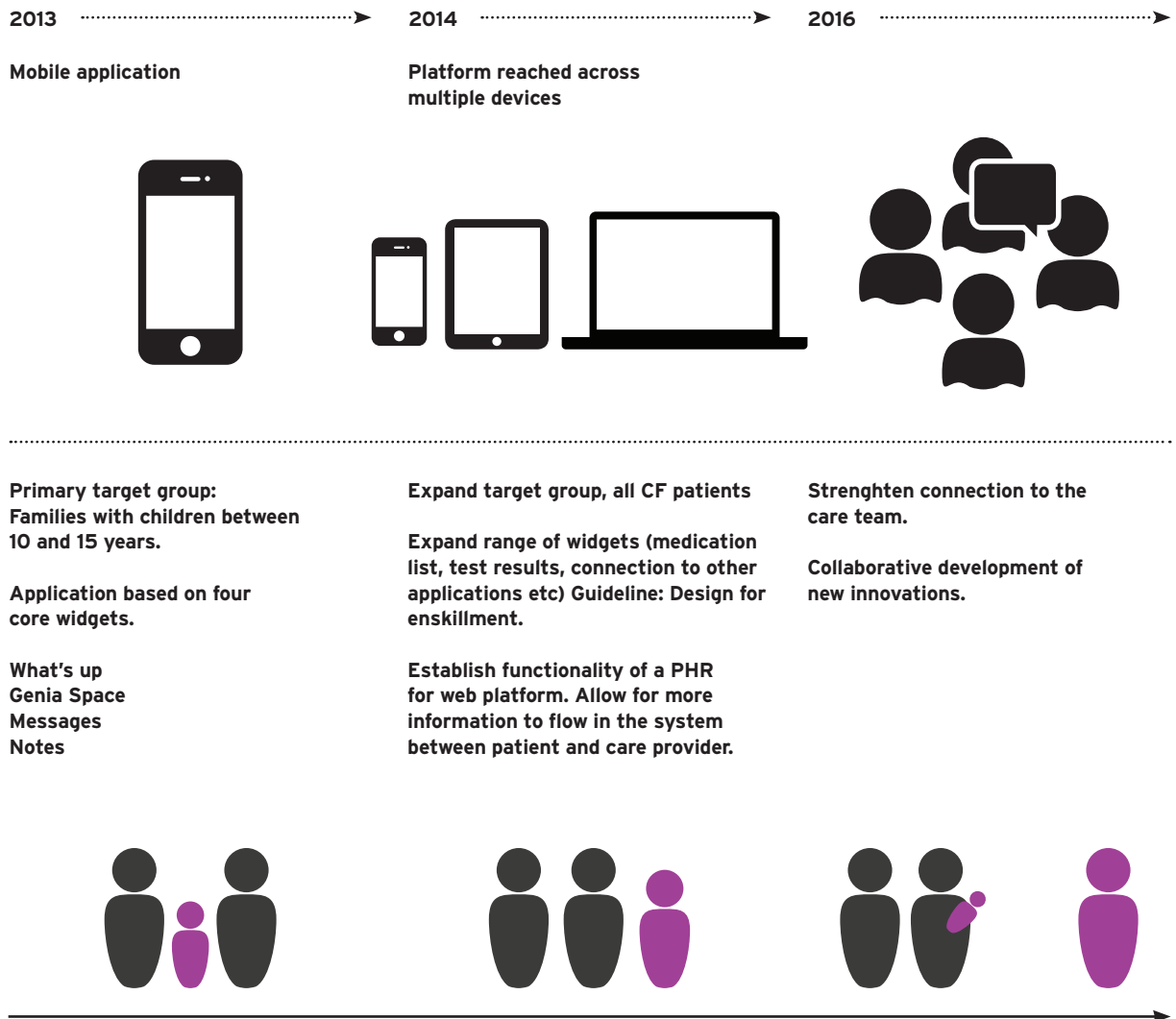


FIGURE 3.40
Sketch of a roadmap for future development and growth of the Genia platform.

4. CONCLUSION

E-HEALTH IS A domain under great expansion and the national healthcare system in Sweden is undergoing vast developments in this area. The hypothesis for this thesis was that the practice of design can be of valuable contribution to the emerging e-health service systems, in creating services that are meaningful, desirable and valuable for both usage in, and in bridging the professional and the private spheres. Research and a practical project has been carried out, focusing on design of a smartphone application aiming to support in daily life with disease and to facilitate collaboration in care of cystic fibrosis. The case is based on a user driven effort of bettering the possibilities for everyone in the clinical microsystem to collaborate for improved outcomes of care.

Empathic design research has given an understanding for how children and their families experience daily life with cystic fibrosis, which has revealed opportunities for how an application can support in daily life. Methods and tools from the field of service design have provided an holistic view on how a mobile health application can be integrated into the context of healthcare and support in points of interaction. Findings from my research support previously stated guidelines for design of healthcare technology, to design for understandability and learning related to daily life, as well as to design for enskilment that grows over time.

A concept has been designed with these findings as a base, where one aim has been to facilitate for co-production of care, where patients and families are collaboratively working together with healthcare professionals to remove barriers for healing. The concept emphasizes collection, sharing and analysis of observations of daily living, as a way to gain individual knowledge, and to form a common point of thought in collaboration.

Opportunities are also seen to support management of care in daily life by giving the means for structuring and sharing information in the private sphere. In addition, the concept aims to promote motivation to treatment adherence amongst children, through an interactive platform, where creating a sense of relatedness with others have been the primary driver.

Previous projects regarding design of healthcare technology proves the challenge in creating designs plastic enough to be used in both the private and the professional spheres (Aarhus et al., 2009, Backonja et al., 2012). My study adds to this challenge, showing a need for a design inclusive enough to be used by a target group where individual experiences and needs, related to disease management, vary greatly.

This thesis also sheds light to the notion of designing not only for pragmatic, but also for hedonic needs, enabling for identity construction, even within the healthcare sphere, in order for electronic devices and services to be embraced by the individuals they are aimed for.

The concept designed in this thesis should be regarded as a proposal for future development of the Genia application. Further iteration and elaboration is recommended. I'm aware that in the next phases of development user interfaces and other applications need to be studied. However, within the limit of this work, the main focus has been in user study and the holistic picture rather than competitive studies or technical applicability. Nevertheless, at the time of writing, the basis from this concept is taken into development for further iteration in real use, through financing from the European Commission.

Lessons learned

WHEN TUNING IN to the process of empathic design, I find that reading blogs was a very useful method. In the blogs people share quite personal experiences which provided me with insights to the subject and helped me prepare for further research. I believe the method can be especially useful when designing in healthcare, or other contexts where the topic for design relates to daily but quite personal matters, and research participants are difficult to reach.

The work in this process have involved design with and for children. I recognize that design with and for children, requires an ability from the designer to adapt methods and tools to the children's way of interpreting and expressing themselves. Having no previous experience from designing with and for children, I found this quite challenging, especially when design related to such personal subject as

chronic disease.

A main challenge for me in this process has been to gain deep enough understanding for life with chronic disease and to design in a context that I was previously entirely unfamiliar with. At the same time, I have needed to gain an understanding for the system of CF-care and the stakeholders in this sphere, as well as knowledge about CF as a disease, in order to understand requirements for design. In all, the context for design has required large amount of research, and participation from many stakeholders. I can agree with Peter Jones, saying that to design in healthcare requires deep knowledge in order to be effective (Jones, 2013), and it takes time to build this knowledge.

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BIBLIOGRAPHY

- AARHUS, R., BALLEGAARD, S. A. & HANSEN, T. R. 2009. The eDiary: Bridging home and hospital through healthcare technology. *Proceedings of the 2009 Eleventh European Conference on Computer-Supported Cooperative Work*. Vienna, Austria.
- AHTINEN, A., MATTILA, E., VAATANEN, A., HYNINEN, L., SALMINEN, J., KOSKINEN, E. & LAINE, K. 2009. User experiences of mobile wellness applications in health promotion: User study of wellness diary, mobile coach and selfrelax. *Pervasive Computing Technologies for Healthcare, PervasiveHealth*. London: IEEE.
- ANDERSEN, M. 2013. *Playing Around With Your Health at Games for Health 2013*. Available: http://www.argn.com/2013/07/playing_around_at_games_for_health/ [Accessed 01 October 2013].
- ARVIDSSON, N. 2006. Overall conclusions this far. In: NORMANN, R. & ARVIDSSON, N. (eds.) *People as Care Catalysts: From being patient to becoming healthy*. Wiley.
- BACKONJA, U., KIM, K., CASPER, G. R., PATTON, T., RAMLY, E. & BRENNAN, P. F. 2012. Observations of Daily Living: Putting the "Personal" in Personal Health Records. *International Congress on Nursing Informatics*. Montreal.
- BALLEGAARD, S. A., HANSEN, T. R. & KYNG, M. 2008. Healthcare in Everyday Life - Designing Healthcare Services for Daily Life. *CHI 2008 Proceedings · Personal Health*. Florence, Italy.

BATALDEN, P. 2013. RE: Patient co-production and collaborative care. Personal e-mail correspondence with Dr Paul Batalden, Professor Emeritus, The Dartmouth Institute, Geisel School of Medicine at Dartmouth, within the Genia project, 4 November.

BATALDEN, P., OGRINC, G. & BATALDEN, M. 2006. From one to many. *Journal of Interprofessional Care*, 20, 549-551.

BATALDEN, P. B. & DAVIDOFF, F. 2007. What is “quality improvement” and how can it transform healthcare? *BMJ Quality and Safety*, 16, 2-3.

BELK, R. W. 1988. Possessions and the Extended Self. *Journal of Consumer Research*, 15.

BEST, G. & HARRIES, J. 2006. The future shape of health care. In: NORMANN, R. & ARVIDSSON, N. (eds.) *People as Care Catalysts: From being patient to becoming healthy*. Wiley.

BISPO, R. & BRANCO, R. 2008. Designing out stigma: the role of objects in the construction of disabled people’s identity. *Dare to Desire: 6th International Design & Emotion Conference*. Hong Kong.

BOVAIRD, T. 2007. Beyond engagement and participation: User and community coproduction of public services. *Public Administration Review*, 846-859.

BOYLE, D. & HARRIS, M. 2009. *The challenge of co-production*. Available: <http://www.nesta.org.uk/publications/challenge-co-production> [Accessed 26 September 2013].

BUCHENAU, M. & SURI, J. F. Experience prototyping. *Proceedings of the 3rd conference on Designing interactive systems: processes, practices, methods, and techniques*, 2000. ACM, 424-433.

BUCKS, R. S., HAWKINS, K., SKINNER, T. C., HORN, S., SEDDON, P. & HORNE, R. 2009. Adherence to Treatment in Adolescents with Cystic Fibrosis: The Role of Illness Perceptions and Treatment Beliefs. *Journal of Pediatric Psychology*, 34 893-902.

BURNS, C., COTTAM, H., VANSTONE, C. & WINHALL, J. 2006. Transformation Design. *RED PAPER 02*, London: Design Council.

CHIRA, P., NUGENT, L., MILLER, K., PARK, T., DONAHUE, S., SONI, A., NUGENT, D. & SANDBORG, C. 2010. Living Profiles: Design of a health media platform for teens with special healthcare needs. *Journal of biomedical informatics*, 43, 9-12.

CHRISTENSEN, C. M., GROSSMAN, J. H. & HWANG, J. 2009. *The innovator's prescription: a disruptive solution for health care*, McGraw-Hill New York.

CONNER, M. & NORMAN, P. 2005. *Predicting health behaviour*, Open University Press.

COOPER, A. & REIMANN, R. 2008. Persona. In: ERLHOFF, M., MARSHALL, T. & BRUCE, L. (eds.) *Design dictionary: perspectives on design terminology*.

COTTAM, H. & LEADBEATER, C. 2004. *RED 01 HEALTH: Co-creating Services*. London: Design Council.

COULTER, A. & ELLINS, J. 2007. Effectiveness of strategies for informing, educating, and involving patients. *BMJ: British Medical Journal*, 7, 24-27.

DETERDING, S., DIXON, D., KHALED, R. & NACKE, L. 2011. From game design elements to gamefulness: defining gamification. *Proceedings of the 15th International Academic MindTrek Conference: Envisioning Future Media Environments*. ACM, 9-15.

EHN, P. Participation in design things. 2008. *Proceedings of the Tenth Anniversary Conference on Participatory Design*. Indiana University, 92-101.

EUROPEISKA KOMMISSIONEN. 2013. *e-Hälsa* [Online]. Europeiska kommissionen. Available: http://ec.europa.eu/health-eu/care_for_me/e-health/index_sv.htm [Accessed 24 September 2013].

EYSENBACH, G. 2001. What is e-health? *Journal of Medical Internet Research*, 3 (2).

FINANSDEPARTEMENTET. 2004. *Långtidsutredningen*. Available: <http://www.regeringen.se/sb/d/361/a/12076> [Accessed 06 July 2013].

FOX, S. & DUGGAN, M. 2013. *Tracking for Health*. Pew Research Center's Internet & American Life Project.

FREIRE, K. & SANGIORGI, D. 2010. Service design and healthcare innovation: From consumption to coproduction and co-creation. *2nd Nordic Conference on Service Design and Service Innovation*, Linköping, Sweden.

GEGNER, L. & RUNONEN, M. 2012. For what it is worth Anticipated Experience Evaluation. In: J. BRASSETT, P. H., G. LUDDEN, M. MALPASS & J. MCDONNELL, (ed.) *International Design and Emotion Conference, 2012 London*.

GIFFIN, N. J., RUGGIERO, L., LIPTON, R. B., SILBERSTEIN, S. D., TVEDSKOV, J. F., OLESEN, J., ALTMAN, J., GOADSBY, P. J. & MACRAE, A. 2003. *Premonitory symptoms in migraine: An electronic diary study*. *Neurology*, 60.

HASSENZAHN, M., DIEFENBACH, S. & GÖRITZ, A. 2010. Needs, affect, and interactive products—Facets of user experience. *Interacting with Computers*, 22, 353-362.

HORTENSIUS¹, J., KARS, M. C., WIERENGA, W. S., KLEEFSTRA, N., BILO, H. J. & BIJ, J. J. V. D. 2012. Perspectives of patients with type 1 or insulin-treated type 2 diabetes on self-monitoring of blood glucose: a qualitative study. *BMC Public Health*, 12.

HYYSALO, S. 2004. *Uses of innovation: Wristcare in the practices of engineers and elderly*, University of Helsinki, Department of Education.

JACOBSON, S. 2010. Overcoming the Stigma Associated with Assistive Devices. *Proceedings of Blatantly Blues, the 7th International Conference on Design & Emotion*, Chicago, USA.

JEONGEUN KIM, HONGJU JUNG & BATES, D. W. 2011. History and Trends of "Personal Health Record" Research in PubMed. *Healthc Inform Res*, 17(1), 3-7.

JONES, P. H. 2013. *Design for Care: Innovating Healthcare Experience*. [Kindle Mac Version] Retrieved from Amazon.com.

KAHNEMAN, D. 2010. *The riddle of experience vs memory* [Online]. Available: http://www.ted.com/talks/daniel_kahneman_the_riddle_of_experience_vs_memory.html [Accessed 11 October 2013].

KANKAINEN, A., VAAJAKALLIO, K., KANTOLA, V. & MATTELMÄKI, T. 2012. Storytelling Group—a co-design method for service design. *Behaviour & Information Technology*, 31, 221-230.

KILBOURN, K. & BUUR, J. 2007. The patient as skilled practitioner. *Nordes*, Stockholm.

KLASNJA, P. & PRATT, W. 2012. Healthcare in the pocket: Mapping the space of mobile-phone health interventions. *Journal of Biomedical Informatics*, 45, 184-198.

KOPP, J. 1988. Self-monitoring: A literature review of research and practice. *Social Work Research and Abstracts*, 24, 8-20.

KURVINEN, E., KOSKINEN, I. & BATTARBEE, K. 2008. Prototyping social interaction. *Design Issues*, 24, 46-57.

LANDSTINGET I ÖSTERGÖTLAND. 2013. *Nationella Kvalitetsregister, Ansökan 2013*. Available: <http://www.kvalitetsregister.se/register/nervsystemet/cf-register> [Accessed 29 December 2013].

LIND, M. 2013. *Software Development Kit och informationsinfrastruktur* [Online]. Karolinska Institutet. Available: <http://ki.se/ki/jsp/polopoly.jsp?d=42672&a=163445&l=sv> [Accessed 12 September 2013].

MAGER, B. 2008. Service Design. In: ERLHOFF, M., MARSHALL, T. & BRUCE, L. (eds.) *Design dictionary: perspectives on design terminology*. Birkhäuser Verlag.

MALONE, T. W. & LEPPER, M. R. 1987. Making learning fun: A taxonomy of intrinsic motivations for learning. In: R. E. SNOW & FARR, M. J. (eds.) *Aptitude, Learning and Instruction III: Conative and affective process analyses.*: Lawrence Erlbaum.

MATTELMÄKI, T. 2006. *Design probes*, University of Art and Design Helsinki.

MATTELMÄKI, T., VAAJAKALLIO, K. & KOSKINEN, I. 2014. What Happened to Empathic Design? *Design issues* 30(1).

MCWILLIAM, C. L. 2009. Patients, persons or partners? Involving those with chronic disease in their care. *Chronic Illness*, 5, 277-292.

MICROSOFT HEALTHVAULT. 2013. *HealthVault* [Online]. Available: <https://www.healthvault.com/se/sv> [Accessed 7 October 2013].

NESTA, I. U. 2012. *Working towards people powered health*. Available: http://www.nesta.org.uk/publications/assets/features/working_towards_people_powered_health [Accessed 10 October 2013].

NORMANN, R. 2006a. Health care - victim of the industrial model? In: NORMANN, R. & ARVIDSSON, N. (eds.) *People as Care Catalysts: From being patient to becoming healthy*. Wiley.

NORMANN, R. 2006b. Who and where is the customer? In: NORMANN, R. & ARVIDSSON, N. (eds.) *People as Care Catalysts: From being patient to becoming healthy*. Wiley.

PATRICIA FLATLEY BRENNAN, S. D., GAIL CASPER 2010. Project HealthDesign: Rethinking the power and potential of personal health records. *Journal of Biomedical Informatics*, 43, S3-S5.

PEEL, E., PARRY, O., DOUGLAS, M. & LAWTON, J. 2003. Blood glucose self-monitoring in non-insulin-treated type 2 diabetes: a qualitative study of patients' perspectives. *British Journal of General Practice*, 54, 183-188.

- QUANTIFIED SELF. 2013. *Quantified Self* [Online]. Available: <http://quantifiedself.com/> [Accessed 31 July 2013].
- RYAN, R. M. & DECI, E. L. 2000. Intrinsic and extrinsic motivations: Classic definitions and new directions. *Contemporary educational psychology*, 25, 54-67.
- RYAN, R. M., PATRICK, H., DECI, E. L. & WILLIAMS, G. C. 2008. Facilitating health behaviour change and its maintenance: Interventions based on self-determination theory. *The European Health Psychologist*, 10, 2-5.
- WALFORD, S., GALE, E. A. M., ALLISON, S.P., TATTERSALL, R.B. 1978. SELF-MONITORING OF BLOOD-GLUCOSE: Improvement of Diabetic Control. *The Lancet*, 311, 732-735.
- SANANDAJI, N. 2012. *Den innovativa vården*, VINNOVA-Verket för Innovationssystem.
- SANDERS, E. B. N. & STAPPERS, P. J. 2008. Co-creation and the new landscapes of design. *CoDesign: International Journal of CoCreation in Design and the Arts*, 4:1, 5-18.
- SANGIORGI, D. & MERONI, A. 2011. *Design for Services*, Ashgate Publishing Group.
- SOCIALSTYRELSEN. 2013. *Ovanliga Diagnoser - Cystisk fibros* [Online]. Available: <http://www.socialstyrelsen.se/ovanligadiagnoser/cystiskfibros> [Accessed 04 September 2013].
- STAR, S. L. & GRIESEMER, J. R. 1989. Institutional ecology, translations' and boundary objects: Amateurs and professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39. *Social studies of science*, 19, 387-420.
- STATSRÅDSBEREDNINGEN. 2013. *HälsaFörMig* [Online]. Regeringskansliet. Available: <http://www.regeringen.se/sb/d/17060/a/211054> [Accessed 12 September 2013].
- STEEN, M. 2011. Tensions in human-centred design. *CoDesign*, 7, 45-60.

STEINHUBL, S. R., MUSE, E. D. & TOPOL, E. J. 2013. Can Mobile Health Technologies Transform Health Care? *Journal of the American Medical Association*. Available: http://list.umassmed.edu/read/attachment/136612/1/Steinhubl_JAMA_MHT%20Transform%20HealthCare_2013.pdf [Accessed 05 November 2013].

SWAN, M. 2009. Emerging Patient-Driven Health Care Models: An Examination of Health Social Networks, Consumer Personalized Medicine and Quantified Self-Tracking. *International Journal of Environmental Research and Public Health*, 6, 492-525.

TANG, P. C., ASH, J. S., BATES, D. W., OVERHAGE, J. M. & SANDS, D. Z. 2006. Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption. *Journal of the American Medical Informatics Association*, 13, 121-126.

VINNOVA. 2013. SDK [Online]. Available: <http://sdk.minavardkontakter.se/en/om-sdk/> [Accessed 8 November 2013].

VÅRDGUIDEN. 2013. Cystisk Fibros [Online]. Available: <http://www.1177.se/Stockholm/Fakta-och-rad/Sjukdomar/Cystisk-fibros/#section-5> [Accessed 2013-11-11].

VÅRDKONTAKTER, M. 2013. Välkommen till SDK för vårdens framtida IT-tjänster [Online]. Available: <http://sdk.minavardkontakter.se/> [Accessed 2013-09-12 2013].

WHO. 2013. *Genes and human disease* [Online]. World Health Organization. Available: <http://www.who.int/genomics/public/geneticdiseases/en/index2.html> [Accessed 5 May 2013].

ZEMANICK, E. T., HARRIS, J. K., CONWAY, S., KONSTAN, M. W., MARSHALL, B., QUITTNER, A. L., RETSCH-BOGART, G., SAIMAN, L. & ACCURSO, F. J. 2010. Measuring and improving respiratory outcomes in cystic fibrosis lung disease: Opportunities and challenges to therapy. *Journal of Cystic Fibrosis*, 9, 2010, 1-16.

ZICHERMANN, G. 2011. *Intrinsic and Extrinsic Motivation in Gamification*. Available: <http://www.gamification.co/2011/10/27/intrinsic-and-extrinsic-motivation-in-gamification/> [Accessed 4 October 2013].

ZIMMERMAN, J. 2009. Designing for the self: making products that help people become the person they desire to be. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 395-404.

APPENDIX

DESCRIPTION OF THE EXISTING APPLICATION

IN THE APPLICATION it is possible to assess daily health-state by answering questions on different scales. These are questions taken from the paper-based “How’s your health form” available in the waiting room at the clinic. The questions refer to CF-related symptoms that are of interest to the clinicians at the monthly check-ups when evaluating patients’ state of health, and respiratory health state in particular. Apart from the clinical questions the application also allows the user to make free notes and take pictures to document around the personal health. There is also a possibility to store data of respiratory function measured at home with a micro spirometer.

Before the monthly checkup it is possible to fill in and send information to the clinic by e-mail. This information is structured in the same manner as the pre-visit questionnaire provided by the clinic. The thought behind this function was that if the CF-team could have information about the patient some time before the visit, the visit could be better prepared and planned for.

The application is designed for several individuals to be connected to the same account. The patient is the administrator of the account, while others can be connected to it, such as family members or other persons related to the patient. The data that is put in the app is shown to all parties connected to one account. This means family members can all make notes that are stored in the patient’s account and shown to all people connected to the patient, all in the private sphere.

The patient who is registered to an account owns all the collected data for that specific account. The data is stored in a server and can only be reached by the patient and the persons connected to the patient’s account. All other types of data sharing to other parties, e.g for clinical research purposes, must be authorized by the patient or



his/hers legal guardians.

When the application was launched in October 2012 it was promoted via a patient network on Facebook and to the Swedish patient association for cystic fibrosis. Since the launch in October 2012 the application had in May 2013 been downloaded by 50 patients. Of these 50 downloads there were only three frequent users.



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